2004

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DOI: <https://doi.org/10.31979/etd.37fg-syfr>

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**AN EXPLORATION OF BEING AND HAVING
ALLIES IN THE INDEPENDENT LIVING MOVEMENT**

A Thesis

Presented to

The Faculty of the Department of Health Science

San José State University

In Partial Fulfillment

Of the Requirements for the Degree

Master of Public Health

By

Anji Buckner

August 2004

UMI Number: 1424489

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ABSTRACT

AN EXPLORATION OF BEING AND HAVING ALLIES IN THE INDEPENDENT LIVING MOVEMENT

By Anji Buckner

This qualitative study explored the experience of having and being allies in the Independent Living Movement (ILM). A purposive sampling strategy was used to create a diverse sample of ten adults who had participated in the ILM as having or being allies. Through semi-structured open-ended interviews, participants had an opportunity to share their experiences in a movement created by and for people with disabilities. Experiences shared in this study offer insight into the complexity of allied relationships in the ILM.

The analysis of participant responses explored key concepts and five major themes related to allied relationships in the ILM emerged. Key concepts included disability, allies, and independent living. Five emergent themes were (a) commitment, (b) trust, (c) expectations and assumptions, (d) leadership, and (e) the importance of allies. These results indicate that despite challenges, allied participation in the ILM is necessary and desired.

ACKNOWLEDGEMENTS

I sincerely appreciate all of my allies who helped me along this amazing journey. Thank you for your unrelenting support, guidance, and wisdom. This research is dedicated to changing the paradigm of disability and building strong allied relationships to work together for social changes.

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CHAPTER ONE

Introduction

The purpose of this research was to explore the experience of being allies and having allies in the Independent Living Movement (ILM). Spearheaded by Ed Roberts, the ILM opened the first Independent Living Center (ILC), in Berkeley, California, in 1972. In the 30 years since, the ILM has grown to an international movement with more than 400 Independent Living Centers worldwide. Using qualitative methodology, this research provided people who have been involved in allied relationships in the Independent Living Movement an opportunity to share their experiences in a movement created by and for people with disabilities. Specifically, this study examined the unique challenges, contributions, risks, and benefits of being allies and having allies in this important social movement.

Statement of the Problem

The Independent Living Movement (ILM) encompasses three domains: a grassroots movement, a philosophy, and a nationwide community of Independent Living Centers (Deegan, 1992). The movement's central concept, independent living, assumes that disability is a social problem, rather than an individual experience, and that it is the right, not the privilege, of people with disabilities to live and participate in community life. Furthermore, the concept of independent living (IL) posits that helping and fostering the transition to, or maintenance of, independent living and recognizing an individual's right to self-determination are fundamentally social responsibilities. According to ILM activist Judy Huemann, independent living is "the ability of disabled people to participate

actively in society: to work, have a home, raise a family if they wish, in sum to decide their own futures according to the cultural context in which they live” (Scotch, 1989, p. 393). The goals of the Independent Living Movement are, (a) to promote the equal rights of people with disabilities, (b) foster the personal empowerment of individuals with disabilities, and (c) reshape the way professionals and society as a whole think about disability (DeJong, 1979). While all three of these goals shape the experience of allies in the Independent Living Movement, the second and third goals have particular implications for allied relationships.

The Independent Living Movement works towards its goals through the promotion of its philosophy, advocacy, and Independent Living Centers. Through its vision and philosophy, the ILM seeks to increase visibility and awareness of the lives and experiences of people with disabilities, with the ultimate goal of changing the paradigm through which disability is understood. The movement’s efforts in grassroots activism have contributed to improved access to social participation through significant civil rights legislation, such as the Americans with Disabilities Act, which mandates equal rights and full social participation for people with disabilities. Finally, Independent Living Centers are service-oriented, consumer-controlled organizations which promote a variety of programs including advocacy, peer counseling, independent living skills, personal assistance, benefits and housing resources, and information and referral (Bruckner & Bruckner, 2000; DeJong, 1979).

Despite the strong conviction of its founders that the Independent Living Movement is by and for people with disabilities, the practical, visionary, and legal goals

of the ILM are carried out by many, including those who are allies and those who have allies, working together. The term “ally” is used in social change and social movement literature in reference to groups or individuals who work together towards a common goal. The structure of the ILM often makes it difficult to differentiate between those who are allies and those who have allies, as both occupy similar positions, such as activists, advocates, ILC staff, and researchers.

The challenge in distinguishing between those who are allies and those who have allies in the Independent Living Movement is more complex than in other social movements. For example, the distinction was most apparently obvious in the Civil Rights Movement of the 1960s, with the visible difference between black activists and white allies. In contrast, in the Lesbian and Gay Rights Movement, the distinction between heterosexual allies and gay men and lesbians is not always as visibly obvious. This distinction is even more difficult with disability for two primary reasons. First, there are invisible disabilities, such as traumatic brain injury, chronic fatigue syndrome, and bipolar disorder, which can make it impossible to visually distinguish between those who are allies and those who have allies. Second, disability is often perceived as a universal and fluid phenomenon in which an individual may acquire a disability of any degree, at any time, and for any length of time.

An additional challenge in differentiating between people who are allies and people who have allies is that those who benefit from the achievements of the Independent Living Movement go beyond people with disabilities. For example, the structural changes resulting from the passage of the Americans with Disabilities Act,

such as the widening of doorways and sidewalk curb-cuts, were immediately appreciated by people pushing strollers, who were able to more easily participate in public activities with their children. Similarly, universal design is a concept that encourages product designers and architects to create goods and structures that are designed for everyone regardless of ability. A good example is the use of door handles, rather than door knobs, which are easier for many people to use, including children, someone with weak upper body strength, or someone carrying groceries (Pelka, 1997).

Another aspect of the Independent Living Movement which complicates the ally relationship even more is the complex nature of a social movement based on independence and self-help. Anecdotal evidence suggests that the ILM's fundamental emphasis by and for people with disabilities, the enforcement of the self-help and peer education concepts, and the utilization of slogans such as, "Nothing About Us, Without Us" make it difficult to accept, acknowledge, and encourage the help of allies (Charlton, 2000; DeJong, 1979). Disability scholars and activists recognize that a potential challenge or risk of a movement based on self-help principles is that it promotes a go-it-alone approach (Charlton, 2000). The "go-it-alone" approach is functionally and politically problematic for two reasons. First, many people with disabilities do require assistance or help from others (Charlton), and second, the approach may lead to the alienation of potential supporters (Steenhout, 2001).

This discussion has introduced some of the challenges in identifying who the allies are and their experiences in the movement. However, one further aspect of this complex relationship is the possibility that being an ally can be difficult, confusing, and

at times painful. Such complexities are shared by allies among all social movements; however, each movement offers its own unique challenges. In social movements for culturally and socially marginalized groups of people, being an ally necessarily includes being able to critically analyze and understand the relationships between privilege, power, oppression, and prejudice. For example, in the Civil Rights Movement of the 1960s, white allies were often faced with severe personal and social consequences of their actions, such as social rejection, community ostracism, loss of job opportunities, and being the victims of violent acts (Brown, 2002).

In the Independent Living Movement, the consequences of being an ally may not be physically harsh as they were in the Civil Rights Movement, but they can be emotionally rigorous and awkward. Potential allies must work through, and gain an understanding of, what it means to have a disability in our culture, and begin to comprehend the pervasiveness of disability oppression and discrimination. Furthermore, the literature suggests that allies in the ILM are challenged by unclear expectations and roles, negative attitudes, and an openly acknowledged fear among movement leaders of losing power and control over “their” movement (Barnartt & Scotch, 2001; Breslin, 2000; Danforth & Rhodes, 1997; DeJong, 1979; Jones, C., 2000; Mackelprang & Salsgiver, 2001; McCarthy, 2002; O’Toole, 2000; Roberts, 2000; Shapiro, 1994; Steenhout, 2001; “University of California’s Cowell Hospital,” 2000). Despite these important challenges, and suggestive accounts, very little research has been done on the experience of being and having allies in the Independent Living Movement.

Research Questions

This research was designed to explore the meaning and experience of allies in the Independent Living Movement as experienced by both those who are allies and those who have allies. This research posed the following questions:

1. How is “ally” defined by individuals, with different perspectives and life experiences, who are participating in the Independent Living Movement?
2. What is the experience and meaning of being or having an ally to individuals participating in the movement?
3. What are the assumptions, held by different people involved in the Independent Living Movement, about the allied relationship?
4. What are the perceived benefits and challenges of being or having allies in a movement by and for people with disabilities?
5. How do those who have allies and those who are allies work collaboratively to achieve the goals of the Independent Living Movement?

Research Objectives

This research was designed to meet the following objectives:

1. To explore the experience of both being and having allies by participants in the Independent Living Movement (ILM).
2. To provide an opportunity for people to reflect on and articulate their experiences in the ILM.
3. To produce useful data for public health professionals and community advocates to promote the independent living philosophy and participate in the ILM.

4. To add to the literature on social movement participation, the Independent Living Movement, and community organizing.

5. To facilitate and stimulate discussion of the role and relationships of allies in community organizing for health.

Methodology

This study was designed to capture the meaning and experience of allies in the Independent Living Movement. Qualitative methods are appropriate “if one is interested in the respondents’ own interpretation and wording with respect to their behavior, their motives, emotions and experiences in the past and the present” (Heyink & Tymstra, 1993, p. 300). Qualitative researchers believe that people construct their own personal accounts of events and that these subjective constructions are unique to an individual in a particular context. Within this framework, qualitative researchers acknowledge that multiple realities exist, which is precisely what the researcher is interested in (DePoy & Gitlin, 1998; Heynick & Tymstra, 1993; Locke, Wyrick, & Silverman, 2000).

This research was guided by the philosophical foundation of naturalistic inquiry, which acknowledges the complexity of the human experience, the notion that multiple realities can and do exist, the relationship between individuals and their social environments which creates the meaning of an experience, and that “those who have the experiences are most knowledgeable about them” (DePoy & Gitlin, 1998, p. 28). From this perspective, the meaning of being or having an ally in the Independent Living Movement is known best by those individuals involved in the movement who have experienced the phenomena directly.

Additionally, this research adopted the social model of disability as the framework for understanding and communicating respectfully and appropriately with Independent Living Movement participants and within disability culture. This social model posits that “disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment” (WHO, 2001, p. 21). The social model of disability looks to society to accept the responsibility of making the changes necessary to encourage full social participation among people with disabilities. The vision for people with disabilities within the social model emphasizes inclusion and integration of differences, rather than exclusion and segregation.

This study utilized a purposive sampling strategy to create a diverse sample of 10 participants, with and without disabilities, aged 18 and over. Sampling recruitment began in the San Francisco Bay Area with Independent Living Center staff and board members, followed by snowball sampling to generate additional participants. The sampling goal was to collect many diverse perspectives among people who participate in the Independent Living Movement as having or being allies.

A semi-structured interview protocol was developed specifically for this study. The protocol consisted of a number of queries and probes, but no script was followed (see Appendix A). Queries were formulated based on the research question and objectives. Probes were utilized at the researcher’s discretion, to enhance the queries and were specific to the responses by each participant. The protocol was designed to elicit dialogue and discussion on the complex relationship and experience of having or being an ally in the Independent Living Movement.

Tape recorded interviews were transcribed verbatim. The interviews were analyzed for common themes and cross-cutting issues regarding the experience of being and having allies in the Independent Living Movement. Each interview transcript was read thoroughly. Pertinent topics and themes were highlighted and subsequently pulled from the interview and organized in conceptual categories. Categories of data were then coded according to the topic. Initial categories established after completing the first few interviews were used as the basis for analysis of further interviews. As new data emerged they were incorporated into previously identified categories or was used to create a new category.

A research protocol was submitted to the Institutional Review Board (IRB) at San José State University in May, 2003 (see Appendix B). The proposal included a description of the study, the research plan, sample queries, and an informed consent form. The consent form for this study indicated that there was no foreseeable risk to participants and that any participant had the option to withdraw from the study at any time (see Appendix C). Data collection waited two months until the IRB was able to review and approve the proposal (see Appendix D). Informed consent was given prior to the start of each interview.

In order to protect the confidentiality of research participants, all interviews were assigned a numeric code that was known only to the investigator. Participant names were separated from the data after the interviews were completed. The numeric code was the only identifier used from that point forward. All research materials which contained confidential data were kept in a locked cabinet, accessible only to the investigator.

Furthermore, participant confidentiality was upheld in data reporting by ensuring that all data were free from identifiable characteristics.

Definitions

The following conceptual definitions were used in the design of this research.

Operational definitions were determined by individual research participants.

Ally.

Groups or individuals who work in support of the priorities of an individual or group, based on a broad or common vision.

Disability.

“The loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers” (Finkelstein, French, Oliver and Swain, 1993, p. 28).

Impairment.

“The lack of part or all of a limb..., organ or mechanism of the body” (Finkelstein et al., 1993, p. 28), physical, mental, or cognitive.

Limitations

Several limitations in the research design were identified before the study began. As previously discussed, the results are limited in generalizeability, as this study did not attempt to understand the universal experience of being or having allies in the ILM. However, the study design, based on the conceptual framework of naturalistic inquiry, was more concerned with “understanding the richness and depth within one context and

with the capacity to retain unique meanings that are lost when generalization is a goal” (DePoy & Gitlin, 1998, p.102). Additionally, while this study made efforts to include a diverse sample of individuals, it did not attempt to analyze racial, gender, sexual, or ethnic differences among participants in the ILM. A final limitation of the research design was the reliance on self-reported data, which inevitably contains potential inaccuracies due to an individual’s memory, differing interpretations of events, and varying communication styles.

Significance

In a multicultural society in which our differences are increasingly abundant, it is becoming ever more important to have the capacity and desire to forge relationships across these differences and work amongst a variety of people to achieve common goals. On an individual level, since life situations are constantly changing, we never really know when we will need the help of others. Recognizing the imminence of change and the expanding diversity among populations, this study is at the forefront of understanding the challenges, risks, and benefits of people uniting across differences and working together towards a unified vision.

This research has significance for several disciplines beyond public health. The results illustrate ways in which people have worked within the ILM to improve the lives of people with disabilities. They also offer guidance for other community activists and public health professionals to work successfully and appropriately within the Independent Living Movement. At the community level, this research has the capacity to inform the nature of allied relationships and ultimately cultivate the development of improved health

promotion programs designed specifically to enrich the health and well-being of people with disabilities. In the health promotion and community studies arenas, this research will assist community activists in becoming effective change agents, better equipped to work closely and effectively with people with disabilities. Finally, in the social science field, this research has the capacity to influence and encourage future research relating to the experience and role of allies and alliances in other social movements.

CHAPTER TWO

Literature Review

A review of the professional and scientific literature from 1970 to 2003 was conducted. The databases searched included Journals@ovid, JSTOR, Social Sciences Full Text, Sociological Abstracts, and Social Services Abstract. The keywords used for the search were ally, allies, advocates, Independent Living Movement, people with disabilities, disability, participants, social movements, qualitative research, and disability rights movement. Through the process of reviewing the literature, the following topics emerged in relation to the concept of allies and the Independent Living Movement, each of which will be discussed in more detail throughout this chapter: disability in the US, defining disability, disability history, the Independent Living Movement, allies in social movements, and qualitative research methods.

Disability in the United States

An estimated 54 million people with disabilities, defined by functional limitations, are living in the United States (“Disabilities/Impairments”, n.d.; McNeil, 1997; US Department Health and Human Services [HHS], 2000). Assistive technology devices are used by 7.4 million people to improve mobility. The cane, which is the most prevalent, is used by nearly 5 million people. Trends in disability suggest that the proportion of people with disabilities is going to continue to increase in the future, due in part to an increasing number of unintentional and intentional injuries, especially among youth, an expanding aging population, modern medical technology, and improved health

care delivery (McNeil, 1997; National Center for Injury Prevention and Control, 2001; U.S. Department HHS, 2000).

Disability crosses all lines of race, ethnicity, sexual orientation, socioeconomic status, and gender. However, prevalence of one or more disabilities is disproportionately higher among the elderly and aging, and is associated with decreased income and increased poverty (McNeil, 1997). Nearly 1 in 5 (19.4%) people in the U.S. have at least one disability, compared to 54% of people over the age of 65. Only 3 in 10 people with disabilities, of working age, work full or part-time, compared to 8 in 10 people without disabilities. One in 3 adults with disabilities earns less than \$15,000 per year, compared to 1 in 8 for adults without disabilities (Young, 2000).

In addition to these examples of social inequalities, the literature also documents the existence of health disparities between people with and without disabilities in the United States. For example, compared to those without disabilities, people with disabilities report higher levels of stress and less leisure time. Proportionally, people with disabilities receive less frequent preventive medical screenings and routine health care visits (U.S. Department HHS, 2000). In addressing these and other inequalities, the national public health agenda, *Healthy People 2010*, has dedicated an entire chapter to promoting the health of people with disabilities, preventing secondary conditions, and eliminating health disparities (U.S. Department HHS).

The *Healthy People 2010* document is important for both public health professionals and people with disabilities. Both argue that full participation in society is the most important goal. Further, both groups recognize that “full participation cannot be

achieved without eliminating environmental barriers found within architectural structures, technology, organization policies and practices, and social attitudes and without moving toward universal design and nondiscriminatory elements” (U.S. Department HHS, 2000, objective 6.12 ¶ 3).

Defining Disability

Defining disability is important to both the public health and disability rights domains. For both groups, the lack of consistency in defining disability makes it difficult to (a) identify people with disabilities, (b) measure the extent of disability in the United States, (c) assess the impact of disability on social participation, d) assess the prevalence and incidence of secondary conditions, and (e) identify environmental barriers (U.S. Department HHS, 2000).

Disability is defined differently depending on the situation, purpose, and perspective (Barnartt & Scotch, 2001; Oliver, 1993). What emerged from the literature is a diverse collection of definitions which can be grouped into three umbrella models of disability: the government model, the medical model, and the social model.

The Government Model

The government model of disability has two primary functions: first, to provide the foundation for the federal protection of the civil rights of people with disabilities, and; second, to determine eligibility for government benefits programs. According to the US Department of Education (n.d.), there are over 40 different definitions of disability in US federal law. Currently, the most widely used definition is from the civil rights law, the American’s with Disabilities Act (ADA) of 1990. The ADA states that disability exists

in an individual with (a) a physical or mental impairment that substantially limits one or more of the major life activities of such an individual, or (b) a record of such impairment, or (c) being regarded as having such an impairment (American's with Disabilities Act, 1990). An alternative definition of disability that is used by the government to determine Social Security benefits states that "disability means the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months or result in death" (Social Security, n.d.). Within the context of this model, the government assumes responsibility for providing and ensuring basic civil rights, appropriate levels of care, and improving the quality of life of people with disabilities to varying degrees depending on, and changing with, the current medical, political, social, and economic environment.

The Medical Model

The medical model defines disability as a medical diagnosis which requires medical intervention, treatment, and supervision. The definition of disability provided by medical reference texts is "a state of being disabled; deprivation or want of ability; absence of competent physical, intellectual, or moral power, means, fitness, and the like" ("Disability," n.d.). Fundamental assumptions within this definition are that an illness exists, that it is the primary responsibility of the medical professions to fix and eliminate illness and disability, and that the goal of intervention is ideally to return all people to a "normal" status.

Three important criticisms of the medical model of disability were discussed in the literature. First, there are many unintended consequences of the medical model. For example, the medical model fails to account for social factors which affect activity limitation and access; the medical model does not acknowledge the responsibility of government, industry, and society to change systematic exclusion and discrimination of people with disabilities; and lastly, the medical model places judgment and values on what it means to be normal (“A statement”, n.d.).

A second criticism is that the medical model reinforces misconceptions about disability. For example, the notion that people with disabilities are in poor health; that the environment does not play a role in the disabling process; that a standard definition of disability is not necessary; and that public health efforts are focused only on preventing disability (U.S. Department HHS, 2000). Finally, a third criticism is that the medical model assumes that medical research and practice have the capacity to successfully prevent or cure all disabilities, assuming that eliminating disability is a desired goal.

The Social Model

In contrast, the social model of disability fundamentally rejects the assumptions of the medical model. The social model of disability changes the paradigm through which disability is understood by arguing that “disability” is created by social and physical environments which limit opportunities and access to community and social participation by people with impairments. Disability rights activists, organizations, and scholars typically adopt this perspective and promote the use of the two different terms, impairment and disability, to describe the relationship between individuals and their

bodies, the environment, and culture. From this perspective, impairment is defined as the “loss or limitation of physical, mental or sensory function on a long term, or permanent basis” (Finkelstein, et al., 1993, p.28). Alternatively, disablement or disability is defined as “the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal life of the community on an equal level with others due to physical or social barriers” (1993, p.28). The focus of intervention is shifted, from one of requiring medical treatment, to one of advocating for innovations to increase social access and community participation.

The social model of disability assumes that it is the civil right of people with disabilities to participate equally in society, and argues that the medical model of disability fragments the human experience and fails to recognize the abilities of people who are defined solely by medical a diagnosis. Furthermore, the social model asserts that the language used to describe disability and people with disabilities within the medical model generates low self esteem, internalized discrimination, and decreased feelings of self worth, while simultaneously enforcing cultural and political attitudes and norms devaluing people with disabilities (Charlton, 2000). Within the social model of disability there are multiple perspectives of the role and responsibility of society which can be categorized into two different, but related, concepts: social construction and social creation.

Social Construction Perspective. The term, social construction “has been used to describe positions claiming that what is assumed to be understood to be objectively real by persons in the course of their activities is more accurately said to be constructed by

those persons in their thoughts” (Danforth & Rhodes, 1997, p. 359). The social construction of disability means that the term disability, as created and defined by society, is currently conceptualized as a medical problem that should be fixed. From this perspective, the meaning of disability is socially constructed to be in opposition to the similarly constructed meaning of normal. Normal, or non-disabled, represents what is acceptable in behavior, appearance, and abilities. Normal represents the goal, what people who are not normal are striving for. The socially constructed meanings of these two terms establishes a hierarchy of power which further enhances and maintains the opposition between people with disabilities and the non-disabled norm (Linton, 1998). This perspective argues that deconstructing the definition is a necessary first step in changing the attitudes and social perception of people with disabilities. According to Danforth and Rhodes (1997), “deconstruction provides a broad philosophical framework and a process for reading and critically analyzing both written texts and everyday-life contexts, opening up each realm to the possibility of social change” (p. 358).

The social construction perspective argues that disability is not an individual or medical problem and affirms that it is the responsibility of people in society to recognize and change their attitudes towards disability and people with disabilities. From this perspective, it is equally important that individuals with disabilities identify as a person with a disability, and support a future where people with disabilities are recognized as people first, rather than sick, dependent, medical patients.

Social Creation Perspective. The social creation perspective shares the social constructionist vision of changing attitudes, as well as the argument that disability

language is rooted in a “power-over” structure. However, the social creation perspective is ultimately broader and includes multiple dimensions of disability. This perspective recognizes the fluidity of both disability and impairment, arguing that anyone can acquire an impairment for any length of time. Furthermore, disability, or the affects of an impairment on an individual’s social participation, depends on the specific environment, social and structural, and is expected to change under different circumstances and in different environments (“A statement”, n.d.).

The goal of the social creation perspective is to further the concept and recognition of a continuum of varying abilities. This continuum presents disability as a universal experience, which everyone experiences at one time or another during their life, and reflects the multidimensional interaction between the medical, social, and environmental factors that affect an individual’s social participation (“A statement”, n.d.; Altman & Barnartt, 2000). According to the social creation perspective, the ideal society would be fully accessible to all people, in both attitudes and structural environments, regardless of ability.

One popular criticism of the social model of disability, encompassing both the social construction and social creation perspectives, is that it fails to account for the realities of the medical and health-related issues facing many people with disabilities. The World Health Organization shares this criticism and argues that a more accurate model could be called a “biopsychosocial model” which, “synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects” (WHO, 2001, p.21). The

rebuttal argument emphasizes that the separate definitions of disability and impairment account for both the social responsibility and the medical reality, respectively. The social model does not fail to consider the reality of an individual's health, such as pain and weakness, but rather, chooses to define this reality as an impairment, not a disability (Charlton, 2000; Oliver, 1996). Furthermore, one of the primary objectives of the social model is to formulate and promote a framework for disability which clearly rejects the notion and goal of the medical quest to eradicate disability.

In summary, there are a number of ways disability is defined and conceptualized in the literature. These different conceptualizations generally fall into one of three broad categories: government, medical, or social models. The lack of a consistent definition of disability is a complex issue, steeped in history, and clearly impacting the lives and experiences of people with disabilities, and the people dedicated to promoting their health.

Disability History

The history of people with disabilities has largely been ignored by mainstream society. Only recently have people with disabilities begun the arduous process of reclaiming their past and recording events of the present to ensure that their experiences are not forgotten in the future. The history of people with disabilities in the U.S. that emerged from the literature has two differing perspectives. From one perspective, this history is a chronological record of political, medical, and social events or milestones. This account begins with the opening of the American School for the Deaf in 1817, the first school for children with disabilities in the western hemisphere (Pelka, 1997). From

another perspective, the history is a record of evolving trends describing the dominant socio-cultural attitudes towards people with disabilities.

Four unique but overlapping trends were extracted from the literature, each of which will be discussed below. Although historically rooted, these trends continue to impact the lives and social experiences of people with disabilities in the United States. The first trend represents feelings of guilt and shame held by families with children with disabilities (Charlton, 2000; Fleisher & Zames, 2001; Shapiro, 1994). Such feelings have commonly resulted in the segregation and concealment of family members with disabilities. Throughout American history, families were encouraged by healthcare professionals to institutionalize their disabled child, arguing that state institutions provided the best care and education (Pelka, 1997). In 1967, it was estimated that 228,500 people lived in state run institutions (Pelka, 1997).

The second trend emerged as people with disabilities grew in numbers, including thousands of wounded war veterans (Shapiro, 1994), and encompassed the social attitude of pity and sympathy towards people with disabilities. People with disabilities were pitied for their uncontrollable life of misery and pain. Eugenacists argued that people with disabilities were unfit for childbearing and advocated forced sterilization. The extreme advocates argued for mercy killing (Fleisher & Zames, 2001). Attitudes of pity and sympathy were also generated through charity fundraising telethons such as Jerry's Kids, where young people, with visible impairments, were paraded across a stage while the camera zoomed in on their impairments (Fleisher & Zames).

The third trend is the medicalization of disability, which largely began during the polio epidemic of the early to mid-1900s. This trend represents the prevailing attitude that people with disabilities are sick and in need of medical treatment and intervention. This attitude includes a fear of “catching” disability, which was heightened by the virulence of the polio virus. The medicalization of disability is concerned with curing disability and is often socially exemplified through charity organizations and fundraising campaigns, such as the March of Dimes’ goal to eradicate polio and, more recently, cancer organizations’ “race for the cure” (Fleisher & Zames, 2001).

The fourth and most recent trend, which is now the attitude predominantly held by people with disabilities and their allies, is structured around personal empowerment, acceptance, integration, rights and equality, and an expanded view of diversity and a multicultural society. The actual voices of people with disabilities have become important as this final trend continues to develop. These voices are heard most often through the Disability Rights Movement and the Independent Living Movement.

Following in the social and political footsteps of the American Civil Rights Movement and the Women’s Liberation Movement, the Disability Rights Movement is based on the conviction that people with disabilities are a minority population, who are systematically discriminated against and denied basic civil rights (U.S. Department of HHS, 2000). Throughout the 1960s, people with disabilities began pushing for a different place in society, and by the early 1970s, the philosophy and the goal of independent living had become a focus of the Disability Rights Movement (Charlton, 2000).

Independent Living Movement

The philosophy of independent living, and the movement that followed, informally began with a start-up grant for the University of California, Berkeley's, Physically Disabled Student's Program (PDSP). Ed Roberts, a young white male was admitted to UC Berkeley as the first severely disabled student in 1962. Roberts, who had contracted polio at the age of 14, lived in Cowell Student Hospital, the only accessible living option for him at the time. Over the next few years, more severely disabled students joined Roberts in Cowell Hospital, and, in 1970, the residents founded the Physically Disabled Students Program (PDSP) (Pelka, 1997). The PDSP was built on the premise of individual choice and personal empowerment. Run by and for people with disabilities, the services included a wheelchair workshop, information and assistance on modifying cars and vans with lifts, attendant referral services, peer counseling, and advocacy (Shapiro, 1994).

Two years later, this program was modeled in the Berkeley community when the first Center for Independent Living (CIL) was opened by Ed Roberts and John Hessler (Pelka, 1997). In addition to being the starting point for the proliferation of an international Independent Living Movement, the Berkeley CIL was groundbreaking in that it provided a community presence and resource center for people with disabilities developed and staffed by people with disabilities.

The movement's fundamental concept, independent living, assumes that disability is a social problem, rather than an individual experience, and that it is the right, not privilege, of people with disabilities to live and participate in community life.

Furthermore, the concept of independent living (IL) posits that it is a social responsibility to help and foster the transition to, or maintenance of, independent living, and to recognize the individual right to self-determination. According to Independent Living Movement (ILM) activist Judy Huemann, independent living is “the ability of disabled people to participate actively in society: to work, have a home, raise a family if they wish, in sum to decide their own futures according to the cultural context in which they live” (Scotch, 1989, p. 393). The goals of the Independent Living Movement are, (a) to promote the equal rights of people with disabilities, (b) foster the personal empowerment of individuals with disabilities, and (c) reshape the way professionals and society as a whole think about disability (DeJong, 1979). The Independent Living Movement works towards its goals by promoting each of its three domains: a philosophy, advocacy, and Independent Living Centers (Deegan, 1992). Each domain is discussed in greater detail below.

Philosophy of the Independent Living Movement

The movement’s philosophy and vision seek to increase visibility and awareness of the lives and experiences of people with disabilities, with the ultimate goal of changing the paradigm through which disability is understood. Originally argued in 1979 by sociologist Gerben DeJong, changing the paradigm necessarily includes reframing the problem of disability from one of an individual burden to one of a social responsibility, affirming that social attitudes and structural barriers create the most disabling conditions for people with disabilities. In DeJong’s (1979) landmark publication of the independent

living philosophy, he identified five key constructs, which remain virtually unchanged and unchallenged since.

1. People with disabilities have a civil right to access and participate in society.
2. People with disabilities must be afforded the right to take risks, fail, and have the opportunity to learn from their mistakes.
3. People with disabilities are consumers in a market-driven economy, and as such should be involved in the planning and development of services and products which are designed for their use.
4. The independent living paradigm calls into question the medicalization of disability and asserts that people with disabilities know their bodies best.
5. The concept of self-help is a fundamental and necessary component of the IL philosophy, in which skills and experiences are shared amongst people with disabilities (Bruckner; 2000; DeJong, 1979).

Centers for Independent Living

Fully embodying these philosophical components, Centers for Independent Living (CILs) are service-oriented, consumer-controlled organizations that promote a variety of programs including advocacy, peer counseling, independent living skills training, personal assistance, benefits and housing resources, and information and referral (Bruckner, 2000; DeJong, 1979). Operating under the fundamental principles of the IL philosophy, CILs believe that the organization must be community-based, have comprehensive services, address cross-disability issues, respect the experiences of people

with disabilities, and have a goal of full social and cultural integration (Bruckner, 2000; Shapiro, 1994). Furthermore, to ensure the commitment to people with disabilities maintaining the leadership within CILs, there is a written bylaw that states that the board and staff must be consumer controlled, or made up of, at least 51% people with disabilities (Bowen, 1996; Fleisher & Zames, 2001; Pelka, 1997). In a little over 30 years, more than 400 Independent Living Centers have been established world-wide, all sharing similar guiding principles.

Advocacy

The third and final domain of the ILM is grassroots advocacy. This domain has played an important role in the political and legislative changes affecting the lives of many people with disabilities. An example of one of the first achievements of the movement's grassroots advocacy was the fight for curb-cuts on the sidewalks in the city of Berkeley, won by the Rolling Quads, a group of UC Berkeley's PDSP students (Breslin, 2000; Stothers, 2000).

Another example, one of the most visible victories demonstrating grassroots activism of the early Independent Living Movement and Disability Rights Movement, was the national protests against the federal Department of Health, Education and Welfare's (HEW) resistance to signing section 504 of the Rehabilitation Act of 1973. Section 504 would prohibit architectural and economic discrimination on the basis of disability in all federal agencies (Fleisher & Zames, 2001; Pelka, 1997). Massive sit-in demonstrations were organized in 10 cities across the country, and on April 5, 1977, hundreds of people with disabilities led demonstrations and the physical occupation of

federal HEW offices. The most successful occupation was in San Francisco where more than 100 people with disabilities took over the San Francisco HEW building until HEW Secretary Joseph Califano signed Section 504 into law, 23 days later (Fleisher & Zames; Pelka).

A final example, frequently cited as the greatest legal achievement of such grassroots efforts, was the federal civil rights legislation, the Americans with Disabilities Act (ADA). Signed into law in 1990, the ADA mandates that people with disabilities have equal rights and access to participate fully in society (Charlton, 2000; Fleisher & Zames, 2001; Pelka, 1996). National disability rights activists began soliciting input from state disability leaders in the early 1980s and presented a report to the federal government outlining a proposal for the civil rights of people with disabilities (Pelka, 1997). Civil rights legislation became the top agenda item for cross-disability organizations throughout the country. When the ADA was finally signed into law less than 10 years later, thousands of disability activists celebrated on the lawns outside of the White House (Pelka, 1997).

Criticism of the Independent Living Movement

Despite the numerous successes of the ILM, the literature review revealed a number of criticisms. Historically, the movement has under-represented women, people of color, and people with invisible disabilities, such as environmental illness, diabetes, or brain injury (DeJong, 1979). Others have criticized the movement for being too elitist in striving for “independence.” Frequently cited examples include failure to recognize the challenges in managing and staffing in-home support care and personal attendants, or

failure to consider the difficulty of striving for independence within a family or community that is struggling to meet basic needs (Lysack & Kaufert, 1994; Stevens, 2001).

Another criticism of the ILM, which is also a deeply rooted fear, involves the potential for losing power to people without disabilities, and regressing back to the medical model of disability with healthcare professionals controlling the movement (Lysack, 1994; Mackelprang & Salsgiver, 2001). It has been argued that too many professionals are being hired by disability-related organizations and Independent Living Centers. Furthermore, many people with disabilities have developed a genuine distrust of medical professionals based on their own experiences, or someone else's, and fear healthcare professionals occupying positions of power (DeJong, 1979; Mackelprang & Salsgiver, 2001).

A small body of related literature was directed towards healthcare professionals who are working within the ILM. This literature included suggestions to support the able-bodied professional working within the Independent Living Movement (Berrol, 1979; Bowen, 1996; DeJong, 1979; Richardson, 1997). It also included contributions from a handful of professionals writing about their experiences, including feelings of alienation, fear, and distrust by other movement participants (Humphrey, 2000; McCarthy, 2002).

Participation in the Independent Living Movement

Participation in the Independent Living Movement was, and continues to be, difficult to describe. In 1979 DeJong wrote that

The movement's constituency is defined not only by who participates but also by what it advocates. The constituency, in some respects, extends to others who do not actively participate but who nonetheless come under its consciousness-raising spell and thus become informal advocates of its philosophy and ideology (1979, p. 436).

Opportunities for participation exist in the Centers for Independent Living, in advocacy, or in promoting the philosophy. However, the only participant group widely documented and discussed in the literature are people with disabilities. The literature also suggested that ILM participants change according to the issue. One way in which this happens is through efforts to form coalitions and alliances.

Although specific sources were limited, past and current literature suggest that the topic of alliances and coalitions is not new to the Independent Living Movement. These sources argued the importance of forming alliances and discussed which social or political groups could be strong and effective allies (Charlton, 2000; Shapiro, 1994).

Three groups were frequently identified in the literature as potential allies for the Independent Living Movement: people who are aging; lesbian, gay, bisexual and transgender (LGBT) communities; and parents of children with disabilities. However, the literature also revealed challenges in aligning with each of these groups. The aging population does not want to adopt the stigma of disability, and conversely, the disability population does not want to adopt the stigma of homosexuality (Breslin, 2000; Charlton, 2000; Jones, C., 2000; Shapiro, 1994). It was also argued that the parents of people with disabilities are incredibly unrelenting and powerful allies with resources and strong personal interests (Lahr, Cunconan & Brotherson, 1996), but often have difficulties relinquishing control over their children (DeJong, 1997). Due to limited resources

specific to allies in the Independent Living Movement, the literature was also searched for experiences of allies in other social movements.

Allies in Social Movements

Literature on allies and alliances in social movements was relatively diverse, but can be arranged into three broad categories: participation in social movements (Passy & Giugni, 2000, 2001; Platt/Fraser, 1998), the necessity of allies and alliances (Avila, 1997; Barkey, 1991; Gelb 1986; Hojnacki, 1997; Morrow, 1991; Schock 1999), and strategies to form alliances (Canales, 1998; Lawler, 1975; Simon & Gartzke, 1996).

Current literature suggested an emerging interest among social movement theorists in conducting in-depth studies of interpersonal relationships and the experiences of social movement participants, including allies. Two recent publications were identified that addressed this emerging interest in the ally experience. First, Cynthia Stokes Brown, in *Refusing Racism* (2002), identifies and chronicles the lives of four prominent white allies who fought for the civil rights of people of color throughout the 1900s. Brown argues that the stories of white allies are important because they offer insights into the challenges faced by white allies, the difficult decisions they were forced to make, and the fundamental significance of sharing the experiences of white anti-racist role models (Brown).

The second example of the emerging interest in allies was a qualitative study on the experience of heterosexual allies to lesbian, gay and bisexual people (DiStefano, Croteau, Anderson, Kampa-Kokesch, & Bullard, 2000). In their study, heterosexual counselors were asked to complete a survey answering questions about when they acted

or did not act as an ally to their gay, lesbian, or bisexual students. With both examples, the authors recommended further investigation of the ally experience (Brown, 2002; DiStefano, et al, 2000).

While it was not overtly discussed in the literature, it is generally assumed that allies will be helpful in social movements. The literature suggested that the more people who are knowledgeable and advocate for the common cause, the stronger the social movement will be (Shapiro, 1994). It is inferred that without allies, movements will not demonstrate the same level of success in meeting their goals and generating social change.

Summary of the Literature Related to Allies in the Independent Living Movement

This literature review explored the complexity of defining disability, and the historical and philosophical foundations of the Independent Living Movement. Several concerns regarding the ally relationship in the ILM were uncovered in this review. First, only a few studies have been designed to capture the experience or meaning of being or having an ally in any social movement. Second, there are philosophical challenges and criticisms of the Independent Living Movement which may affect the experience of allies, including the fear by people with disabilities that they are losing power and control within the movement to professionals and people without disabilities. Lastly, the lack of consensus in defining disability makes it difficult to determine who the constituents of a movement by and for people with disabilities are, and who the allies are or could be.

The literature also revealed an emerging interest in the topic of allies and the interpersonal relationships of social movement participants. Given the complexities of

the meaning of the experience of disability, and the meaning of being in an allied relationship as a participant in the ILM, a qualitative research design which engages in the process of critical analysis is necessary.

Qualitative Research Methods

Since the 1970s, the professional literature on disability, has expanded beyond merely documenting a chronology of events and milestones to analyzing the experience itself through naturalistic, or qualitative inquiry. According to DePoy and Gitlin (1998) there are four essential characteristics of the philosophical foundation of naturalistic inquiry: (a) “human experience is complex,” (b) “meaning in human experience is derived from an understanding of individuals in their social environments,” (c) “multiple realities exist,” and (d) “those who have the experiences are the most knowledgeable about them” (p. 27).

One way the disability experience has been documented is through oral history projects. The largest collection of oral history interviews is at the Bancroft Library at the University of California, Berkeley. This collection chronicles the life histories of leaders and participants in the early Disability Rights Movement and the Independent Living Movement. A remarkable source of insider knowledge, the collection has served a primary purpose of giving voice and attention to a systematically marginalized group of people (Linton, 2000).

The impact of the life history, or oral history, narrative is two-fold. First, life history provides social, political, and historical data; and, second, the method itself can be a source of individual empowerment, validation, and an opportunity to recognize self-

worth (Hirsch, 1998; Yow, 1994). Life history interviews allow the research participant the opportunity to share their experiences.

The majority of the data incorporating the experience of disability, or of people with disabilities, has been collected via oral history interviews. These collections are an invaluable resource for experiential information on disability and the Independent Living Movement. However, there are other qualitative methods that are designed to critically analyze and discover the meanings of the lived experience (DePoy & Gitlin, 1998). The purpose of oral history is to record and document, but it does not compare or analyze experiences across diverse accounts.

Qualitative research on the experience of being and having allies in the Independent Living Movement (ILM) would provide an invaluable addition to the life history literature by collecting stories of people involved in the ILM and analyzing those accounts across key dimensions of the experience of being and having allies in this important social movement. Additionally, this approach will contribute to our understanding of the experiences of allied relationships in other social movements.

CHAPTER THREE

Methodology

This study used qualitative research methods to explore the meaning and experience of being or having allies in the Independent Living Movement. Qualitative methods were chosen because the primary purpose of this research was to capture the richness and diversity of subjective realities among study participants. Specifically, this study examined the unique challenges, contributions, risks, and benefits of being allies and having allies in the Independent Living Movement.

Research Questions

This research was designed to explore the meaning and experience of allies in the Independent Living Movement as experienced by both those who are allies and those who have allies. This research posed the following questions:

1. How is “ally” defined by individuals, with different perspectives and life experiences, who are participating in the Independent Living Movement?
2. What is the experience and meaning of being or having an ally to individuals participating in the movement?
3. What are the assumptions, held by different people involved in the Independent Living Movement, about the allied relationship?
4. What are the perceived benefits and challenges of being or having allies in a movement by and for people with disabilities?
5. How do those who have allies and those who are allies work collaboratively to achieve the goals of the Independent Living Movement?

Research Objectives

This research was designed to meet the following objectives:

1. To explore the experience of both being and having allies by participants in the Independent Living Movement (ILM).
2. To provide an opportunity for people to reflect on and articulate their experiences in the ILM.
3. To produce useful data for public health professionals and community advocates to promote the independent living philosophy and participate in the ILM.
4. To add to the literature on social movement participation, the Independent Living Movement, and community organizing.
5. To facilitate and stimulate discussion of the role and relationships of allies in community organizing for health.

Definitions

The following conceptual definitions were used in the design of this research.

Operational definitions were determined by individual research participants.

Ally.

Groups or individuals who work in support of the priorities of an individual or group, based on a broad or common vision.

Disability.

“The loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers” (Finkelstein, et al, 1993, p. 28).

Impairment.

“The lack of part or all of a limb..., organ or mechanism of the body” (Finkelstein et al., 1993, p. 28), physical, mental, or cognitive.

Qualitative Research Design

This study was designed to capture the meaning and experience of allies in the Independent Living Movement. Qualitative methods are appropriate “if one is interested in the respondents’ own interpretation and wording with respect to their behavior, their motives, emotions and experiences in the past and the present” (Heyink & Tymstra, 1993, p. 300). Qualitative researchers believe that people construct their own personal accounts of events and that these subjective constructions are unique to an individual in a particular context. Within this framework, qualitative researchers acknowledge that multiple realities exist, which is precisely what the researcher is interested in (DePoy & Gitlin, 1998; Heynick & Tymstra, 1993; Locke, et al, 2000).

Qualitative research presumes that it is appropriate and effective to inquire about peoples’ realities and perspectives through interactions, asking questions, or observations. It is accepted that such interactions make the investigator a primary instrument of data collection (Locke, et al, 2000, p. 97). From this perspective, the researcher ultimately becomes an integral part of the research process. This subjective involvement requires that investigators minimize potential biases by identifying and continually analyzing their own realities, experiences, and assumptions related to the study. Steps taken to reduce potential biases in this study are discussed later in this chapter.

Conceptual Framework

This research was guided by the philosophical foundation of naturalistic inquiry, which acknowledges the complexity of the human experience, the notion that multiple realities can and do exist, the relationship between individuals and their social environments which creates the meaning of an experience, and that “those who have the experiences are most knowledgeable about them” (DePoy & Gitlin, 1998, p.28). From this perspective, the meaning of being or having an ally in the Independent Living Movement is known best by those individuals involved in the movement who have experienced the phenomena directly.

Additionally, this research adopted the social model of disability as the framework for understanding and communicating respectfully and appropriately with Independent Living Movement participants and within the disability culture. This social model posits that “disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment” (WHO, 2001). The social model of disability looks to society to accept the responsibility of making the changes necessary to encourage full social participation among people with disabilities. The vision for people with disabilities within the social model emphasizes inclusion and integration of differences, rather than exclusion and segregation.

Assumptions

Prior to the onset of data collection, the researcher identified several assumptions about the participants, the researcher herself, and the study. The following assumptions apply to this research:

1. Participants would be truthful and honest to the best of their knowledge and ability.
2. Participants have had invaluable experiences and insider knowledge that they would share with the researcher.
3. There would be differences of opinion among participants in general, but more so among those who have longer histories or more experience in the Independent Living Movement.
4. There were many allies within the Independent Living Movement, and their experiences are complex and generally positive.
5. Allied relationships are complex and can not be simplified to the binary: people with disabilities *have* allies and people without disabilities *are* allies.
6. The researcher would be able to recruit and interview at least ten participants representing diverse experiences of being and having allies.
7. The researcher would be able to gain access to participants and create a trustful, respectful, and comfortable environment.
8. The researcher would be able to obtain invaluable information on allies and analyze the data appropriately.
9. The research process and results will have the ability to impact future allied relationships in other social movements.

Informed Consent and Participant Confidentiality

A research protocol was submitted to the Institutional Review Board (IRB) at San José State University in May of 2003 (See Appendix B). The proposal included a

description of the study, the research plan, sample queries, and an informed consent form. The consent form for this study indicated that there was no foreseeable risk to participants and that any participant had the option to withdraw from the study at any time (see Appendix C). Data collection waited two months until the IRB was able to review and approve the proposal (see Appendix D).

Informed consent was given prior to the start of each interview. The researcher discussed the consent form with each participant, explained the study, offered participants a review of the study abstract (see Appendix E), encouraged participants to ask questions, and guaranteed confidentiality. Research participants were assured that their participation was voluntary. Participants were informed of their rights to refuse or decline to answer any question, request necessary breaks or pauses, and withdraw from the study at any time without consequence. Prior to beginning each session, the researcher obtained verbal permission from participants to tape record the interview.

In order to protect the confidentiality of research participants, all interviews were assigned a numeric code that was known only to the investigator. Participant names were separated from the data after the interviews were completed. The numeric code was the only identifier used from that point forward. All research materials which contained confidential data were kept in a locked cabinet, accessible only to the investigator. Furthermore, participant confidentiality was upheld in data reporting by ensuring that all data were free from identifiable characteristics.

Participant Characteristics

All participants lived in the greater San Francisco Bay Area. For decades, the San Francisco Bay Area has played a central role in political and social disability rights activism, making this an ideal study location. A purposive sampling strategy was used to identify participants who represented a variety of perspectives and experiences within the Independent Living Movement. A total of 35 people were identified through 3 key informants. Ten were selected for the study. The final sample represented multiple realities, experiences, and perspectives on the topic of allies in the Independent Living Movement. A detailed discussion of participant characteristics is included in Chapter Four.

Sampling Methods

This study utilized a purposive sampling strategy to create a diverse sample of 10 participants, with and without disabilities, aged 18 and over. All participants were required to have some experience in the Independent Living Movement and the independent living philosophy. This was an important criterion for this study because it should not be assumed that all people with disabilities and/or disability rights activists have knowledge of and experiences with the Independent Living Movement.

Sampling recruitment began in the San Francisco Bay Area with Independent Living Center staff and board members, followed by snowball sampling to generate additional participants. Initially, potential participants were identified through key contacts who were already known to the researcher as professional or academic colleagues. Key contacts included people who identified as being with and without

disabilities. Potential participants already known to the researcher were not excluded when recommended by key informants and when their perspective increased the diversity of the sample. The sampling goal was to collect many diverse perspectives among people who participate in the Independent Living Movement as having or being allies.

As potential participants were identified, key informants first contacted potential participants for permission to give the researcher contact information. The contact information obtained by the key informant included email addresses, phone numbers, and in some instances, a home mailing address.

Following the initial contact by the key informant and approval of the individual, the researcher contacted potential participants via phone first, followed by email. The researcher's first contact generally involved a brief description and discussion of the study, an opportunity to build or establish rapport, and an invitation to participate in the study. If interest was expressed, the researcher mailed or emailed the study abstract (see Appendix E). Upon reviewing the abstract, those who were interested, met the sampling criterion, and added diversity to the growing sample, had the opportunity to schedule an interview and participate in the study. Interviews were scheduled and arranged at the convenience of the participant. The investigator requested locations that were private, comfortable to the participant, and quiet. All participants chose either their home or their office.

At the beginning of each interview, the researcher presented and discussed the informed consent materials (see Appendix C). Participants were told that they could withdraw from the study at any time without consequence. Furthermore, participants

were reassured that declining to participate, or ending the interview prior to completion, would not affect their access to services from the Independent Living Movement. The researcher informed all potential participants directly if they were to be interviewed or not, depending on whether they met the inclusion criterion and added to the diversity of the sample. Additionally, the researcher maintained, and regularly updated, a detailed contact list of all potential participants.

Data Collection Methods and Instruments

Two instruments were used in this study: the interview and the researcher. The first instrument was the interview. In naturalistic inquiry, the interview produces data about the social world by asking participants to talk about their experiences and realities (Silverman, 1998). This study utilized a semi-structured interview with open-ended questions.

Semi-structured interviews are designed to have a number of interview questions prepared in advance but such prepared questions are designed to be sufficiently open that the subsequent questions of the interviewer cannot be planned in advance but must be improvised in a careful and theorized way (Wengraf, 2001, p. 5).

A semi-structured interview protocol was developed specifically for this study. The protocol consisted of a number of queries and probes, but no script was followed (see Appendix A). Queries were formulated based on the research question and objectives. Probes were utilized at the researcher's discretion to enhance the queries, and were specific to the responses by each participant. The protocol was designed to elicit dialogue and discussion on the complex relationship and experience of having or being an ally in the Independent Living Movement.

The interview protocol was modified slightly after the first two interviews when it became important to the investigator to add clarification to two areas: (a) the definition of disability, and (b) the range or continuum of disability. These questions were added because of the lack of consistency in the literature and the researcher's realization that there were similar variations in participant perspectives. Qualitative inquiry provides a research design which is not only capable of changing the design or queries, but actually expects that such changes will occur (DePoy & Gitlin, 1998).

Each participant was interviewed at least once. Three people participated in follow-up interviews. The interviews lasted from one to two and a half hours. Participants were allowed as much time as they needed to answer and respond to questions. Following the interview, field notes were recorded which included the researcher's thoughts and feelings about the participant, the experience, the interview, and potential future directions for data collection and analysis.

All interviews were conducted by the same researcher and were tape recorded using the same equipment. The recorder used was the Panasonic RN-405 microcassette recorder. This particular recorder was chosen due to its compact size, a good quality omni-directional microphone, and a record indicator light. Sixty minute micro-cassette tapes were used and accidental erasure was prevented by immediate removal of the end tabs located on the top of the cassette tape.

The second instrument utilized in this study was the researcher. Naturalistic inquiry recognizes the researcher as a primary instrument arguing that "he or she must interact directly with participants, determining from moment to moment how to behave,

what to notice and record, and how a particular line of inquiry does or does not offer promise for answering the research question” (Locke, et al, 2000 p. 99). The researcher is an experienced oral history interviewer, with knowledge and experiences in the Independent Living Movement and the Disability Rights Movement, both of which were important characteristics affecting the results of this study. For example, the researcher’s experiences in oral history provided confidence with the skill and quality of tape recorded interviewing, and provided the opportunity to practice and refine active listening skills. Active listening affected the interviewer’s ability to hear and ask the appropriate probing questions at the right time and to acknowledge and support the respondent without interrupting or influencing the direction of the respondent’s thoughts.

Similarly, the researcher’s personal experiences with people with disabilities and the Independent Living Movement were important attributes affecting the study results. These experiences provided the researcher with a genuine and personal motivation for undertaking the research which allowed the researcher to gain access to the community, decrease potential fear or skepticism, and increase trust and credibility.

Data Analysis

Tape recorded interviews were transcribed verbatim. The interviews were analyzed for common themes and cross-cutting issues regarding the experience of being and having allies in the Independent Living Movement. Each interview was read thoroughly, and pertinent topics and themes were highlighted and subsequently pulled from the interview and placed in categories. Categories of data were then coded according to the topic. The initial categories, established after completing the first few

interviews, were used as the basis for analysis of further interviews. Emerging data were incorporated into previously identified categories or used to create a new category.

This comparative and reflective process continued throughout data collection. Once all data had been collected, the final categories were analyzed independently and in relationship to one another to reveal the underlying themes (DePoy & Gitlin, 1998). At the completion of data analysis the researcher had identified several key concepts and themes related to the concept of allies in the Independent Living Movement. The researcher chose, at this point, to report all data without disclosing or identifying participant characteristics, such as age, gender, allied perspective, or disability status. Reasons for this decision are discussed in Chapter Five.

Reducing Potential Bias

This research protocol incorporated four key steps for reducing potential biases and augmenting credibility and trustworthiness. Each of these steps is introduced below and discussed in detail in Chapter Five.

First, an interrater reliability test was used to compare the accuracy of the researcher's coding scheme. Thirty percent of the reported data were coded and discussed by the independent rater and the researcher until consensual agreement was achieved.

Second, peer debriefing was used to evaluate the analytical process and interpretation of data during collection, analysis, and reporting. Peers were used extensively throughout the writing process to clarify themes and substantiate the categories. Drafts were shared several times with thesis committee members, offering multiple opportunities to evaluate and debrief during data collection and analysis. All of

the reviewers who read the emerging analysis asked clarifying questions engaging the researcher in a continuous critical analysis of the data.

Third, member checks were used to review and identify the researcher's assumptions and interpretations throughout data collection and analysis. Participant interviews and discussions with key informants provided opportunities to check assumptions and verify the researcher's interpretation of emerging themes and concepts. In addition to satisfying the recruitment needs for the study, conversations with key informants were particularly helpful in checking the accuracy of the researcher's interpretations and presentation of the data.

Lastly, reflexivity was used throughout the entire process to help determine how the researcher's personal experiences and perspectives had shaped and influenced both what was learned and how. Throughout this investigation, the researcher kept a journal which documented personal feelings, attitudes, and ideas that surfaced and emerged during the study. The journal was a particularly useful tool in this study. Key insights that emerged from the process of self-reflection and journaling are discussed in Chapter Five.

The qualitative methods selected and used for this study were effective for addressing the research questions and objectives. The results, presented in Chapter Four, are a synthesis of this multidimensional analysis of both the data and research process.

CHAPTER FOUR

Results

This chapter describes the results of the recruitment process, participant characteristics, and key themes that emerged from the analysis of ten interviews conducted with diverse people with experience in, and knowledge of, the Independent Living Movement (ILM). A total of ten participants were recruited for this study during the summer and fall of 2003. The participants offered a diverse representation of perspectives on allied relationships in the ILM, allowing the exploration of key concepts and the emergence of five major themes related to allied relationships in the ILM. Key concepts included disability, allies, and independent living. Five emergent themes were (a) commitment, (b) trust, (c) expectations and assumptions, (d) leadership, and (e) the importance of allies.

Recruitment Process

The researcher utilized key informants to establish a purposive sample of diverse experiences and perspectives of both being and having allies in the Independent Living Movement. The three key informants were already known to the researcher as either professional or academic colleagues. Key informants self-identified as both people with and without disabilities. The key informants initially helped to establish a small sampling frame from which the researcher identified the first few participants. Following several interviews, the researcher went back to the sampling pool, identified gaps, and returned to the key informants periodically for additional potential participants. Throughout the entire process of data collection and simultaneous analysis, key informants continued to

help identify and contact participants whose perspectives were not yet reflected in the sample. Interestingly, two key informants participated in this study. Each referred the other and each offered a unique perspective that contributed to the overall diversity of the sample.

A total of 35 people were identified as potential participants by the researcher's key informants, of whom 10 were interviewed for the study. All but 4 of the identified potential participants met the inclusion criterion of having experience and/or knowledge of the Independent Living Movement. Among the remaining 31 people identified as potential participants, 15 were identified by key informants as having visible disabilities, 6 were identified as having invisible disabilities, 6 were identified as having no disability, and the disability status was not identified for 4 people.

Thirteen people with knowledge of, and experience with, the Independent Living Movement, representing a variety of different experiences, were invited to participate in the study. Three of the 13 individuals invited did not participate. Of the three, one was unable to participate, one never returned calls, and the third individual was interested, but unavailable at the time.

Participant Characteristics

Ten people were interviewed for this study (See table 1). Three people were identified by key informants as not having disabilities: one professional, one parent, and one personal care attendant. Two people were identified as having visible disabilities: One was born with a disability, and the other acquired a disability as a young adult. Representing different communities, both were considered community activists and early

participants in the Independent Living Movement. The last five people were all identified as having invisible disabilities, four with chronic/long-term disabilities, and one with a temporary disability. Two people were born with disabilities and three acquired disabilities. Two acquired their disabilities slowly over time, and the other person experienced a sudden onset of a temporary disability. Among the five people who were identified as having invisible disabilities, one was an ethnic minority leader of an Independent Living Center, one was a professional, one was a parent of a child with a disability, one worked on state level politics effecting the ILM, and one was an academic professional.

Table 1.

Participant Characteristics

<i>Age</i>		
	<21	0
	21-49	6
	50-75	3
	75 +	1
<i>Gender</i>		
	Female	6
<i>Disability</i>	Male	4
	Visible	2
	Invisible	5
	None	3

Exploring Key Concepts

Study participants were asked questions regarding their general perspectives and conceptualizations of three key concepts: disability, independent living, and allies. Participant responses revealed varied definitions of disability, relatively consistent

understanding of the term “independent living,” and similar theoretical conceptualizations of ally, but different practical ideas and understandings of allies in the Independent Living Movement.

Disability

Participant responses revealed similar concerns over the prevalence of negative attitudes that are harbored towards people with disabilities. In general, participants commented that people with disabilities experience a “lack of respect” and are subject to stereotyping. One participant shared that “there’s the dream some day that disability will be less stigmatized.” The participant continued, “I don’t know that it’s happening. I have my doubts. Even though we’ve made some progress, I don’t think there’s a whole lot of attitudinal change.”

In contrast to the general agreement regarding negative attitudes toward people with disabilities, participants did not share consistent definitions of disability itself. Three different types of definitions emerged from participant responses: individual, social, and categorical. Individual definitions included responses that focused on the individual person with a disability, such as, “A disability is an impairment of some sort.” Another participant’s definition was derived from a personal experience. The participant stated, “disability, from my perspective, has to do with functional limitations that require some sort of adjustment or accommodation on the part of the individual.” Another participant defined disability in relation to ability and the way things can change for an individual:

Disability to me is something beyond the ordinary. We expect people to have two arms and two legs and [a] nose and mouth and [to] see and hear

and walk and that seems to be the expectation. If you are expecting a baby, you hope your kid has all of those things. You hope [the same for] your friends. And then comes auto accidents and polio and all of those kinds of things, as it happened in our family, with polio.

Another variation of the individually-focused definition is iterated by a participant who describes the social realities of having a disability:

It's a practical thing of life, just like all of our practicalities of life. The things that you have to deal with are very daily. It's not mysterious. It just requires cooperation and understanding. ... Some of the physical realities, like accessibility - are different. Curbs are different for people that can't get up them. And it's not going to occur to someone who walks up without noticing. ... Not to mention what the world looks like from a seated position or not seeing at all, or whatever the disability might be. You have a different vision of the world. A different perspective.

In contrast to the individually-focused definitions of disability, some participants shared definitions that had social underpinnings. For example, one participant stated

A disability is a physical or a mental condition that might cause one to either be perceived as not being able to do something in society or actually not being able to do something – running, jumping, thinking. Things of that nature.

A second participant related more personally to a socially-driven definition

What disability means to me is that it's better than being stamped a cripple, but it falls a bit short in terms of [what] I think the social obligations [are]. ... It doesn't address squarely: What should society do so more people with those disabilities - which are not necessarily their fault, and perhaps should not be their burden - what can we do to include more people?... What about being sure that people with disabilities, even though they have them, still get a chance at gosh, a public education. Get a chance at being able to be considered for employment. Get a chance at being able to advance professionally. Like for example, you are.

The final type of definition, categorical, includes participant perspectives that related to specific categories of disability, both formally coded and informally derived. One

participant's definition identified several key interests that define disability. The participant stated

Where the term disability falls under the law, is when there is a substantial limitation in daily activity due to a physical or mental condition. Sometimes the law also includes, ... if you are considered to be disabled, [and you] are not actually. If you had cancer and it's cured, sometimes people still consider you disabled. The law might cover you under that. [Next], the popular definition I think is blind, hearing impaired or a wheelchair user. I think [this is] a very limited definition of disability because there are a lot of non-visible disabilities. [Last,] temporary disability I think is an important one. ...In the course of almost everyone's life, they have some sort of a limitation, maybe it's due to a broken leg or hospitalization, or arthritis, or something to do with aging. Aging impairment. I don't know if temporary is exactly the right word, but it's an expanded definition which I think is a very healthy way to look at the whole disability scene.

Another participant commented on the concept of temporary disability, and introduced the term, "TAB", temporarily able-bodied. This participant said

The expression TAB, as my friend always used, and I always liked that. That we're all one step away, one slip away, from having a disability ourselves. It just makes it, much more, I don't know, easier to feel a connection there, perhaps. In other words, we won't ever be African American, or a boat person in Vietnam, but we will some day very likely end up with a severe disability.

The complexities of invisible disabilities were discussed by several participants within this categorical definition. One participant asserted

The people who had the hardest time would be someone with heart problems who would have trouble walking rapidly or getting across the street in a hurry. That [they] could pass. I remember one particular woman who had trouble crossing the street because cars would honk at her because she wasn't going fast enough and she couldn't. So, one doctor said, "Carry a cane. That should make an obvious sign that this is something." So it made her life a little easier. In some ways, it was her, kind of, acceptance of her being able to do this.

Similarly, another participant shared a perspective on being able to “pass” as a person without a disability:

If you’re blind, or if you’re a wheelchair user, you can’t hide. You can’t be private. Ever. You can’t keep that information ever, from people. So, even after I started identifying myself as a person with a disability, I still didn’t get as many points as they did. In their criteria. Because, those of us with hidden disabilities, we can pass. We can pass for regular people, at times, and they can never, and so there’s an anger against us as well. Damn-it you don’t understand.

The comment above alludes to two related issues that were mentioned by other participants: language and a disability hierarchy. Participants mentioned language and the use of “us” rather than “them,” as well as verbal identification of having a disability by people with invisible disabilities. One participant commented

I notice [the presence of a disability hierarchy] within minutes of meeting people with invisible disabilities, in an independent living training or group where there’s a lot of people with disabilities around. One of the first things they do after they say their name is, [disclose] “I have spinal stenosis and chronic pain,” or “I have a traumatic brain injury.” That [disclosure] just comes along with the introduction.

Another participant discussed “the point system,” noting that people with invisible disabilities receive less “points” on a disability hierarchy. This participant said

The hierarchy of disability, it’s like, if you [had] the most significant [visible disabilities] then you had the most points. If you didn’t have a visible disability then you didn’t have the same power, nor were [you] given the same respect.

A final participant comment illustrates the depth of the complexity of the hidden disability construct. The participant simply observed, “I think there’s always a question, ‘Does she have a disability? Is it invisible? Am I just not seeing it?’”

In summary, participant responses reflected a variety of perspectives and experiences by which disability is conceptualized. Participant responses, which were clustered around individual, social, and categorical definitions, provided insight into the presence and dynamics of differences in the visibility and perceived hierarchy of disability.

Independent Living

The concept of independent living was defined by the majority of participants as being “informed choice” and “having control over life’s decisions.” One individual expressed

In the popular meaning, [independent living] means that you can do everything for yourself. Independent living, in terms of disability, means that you get to decide. You might not be able to do it for yourself, but at least you can choose the people who help you or choose the way you are going to get it done.

Another participant revealed

Independent living, to me, has to do with the individual being able to exercise the same sort of choices that any other individual has. And that, at times, or very often, requires the removal of some sort of barrier, some of which might lie with the individual and some of which might lie in the environment. But, it’s ultimately about being able to make life’s choices just as anyone else would do.

While the majority of participants defined independent living, few specifically included the Independent Living Movement within those definitions. One participant, who did define the Independent Living Movement, recalled personal considerations related to the term:

What it meant to me from my previous knowledge of the independent living philosophy was that this was a movement by and for people with disabilities. Basically working for equal rights and independence in a way

that each person can self-direct and define. Not in a way that the medical or healthcare model defines independence, but promoting independence within the disability community in whatever way that that community or that individual defines independence and advocating for that on a larger level. Also figuring out ways to set up centers in the community to do sort of one-on-one, day-to-day, information and referral services. The other big thing that it meant to me, mostly from my experiences in school, what I learned is that this really is a set up that doesn't want a whole lot of guidance from a health-care professional. That was really at the forefront of my mind when I was applying for this job. It's kinda like, this is an awesome, important movement that I just support wholeheartedly and would love to be a part of, and also, I don't know that I'm going to be really welcome here. That was a big part of my thoughts on Independent Living Movement before I got involved in it.

In general, study participants revealed consistent definitions for the concept of independent living, emphasizing informed choice and having control over life's activities and directions.

Allies

Participants were invited to share their opinions and experiences relating to what an ally is and who allies are. Five key points emerged through this discussion: (a) definitions of ally, (b) necessary characteristics of an ally, (c) actions of an ally, (d) who allies are or could be, and lastly, (e) choosing allies.

Definitions of Ally. Participants shared similar conceptualizations of the meaning of ally. One participant said that “an ally is someone that shares a philosophy,” while others stressed that an ally is “somebody who can be counted on to support, advocate for and with a group of people about whom they feel strongly or with whom they identify [with] on some level.”

Allies were also discussed in terms of a relationship, with particular areas highlighted. As one participant disclosed, “the thing about an ally – you may agree about

one thing, but it doesn't necessarily mean that you'll be best friends." Another participant said that for an allied relationship to work, "you have to have a conversation about what that means," and "it goes back and forth. If you're an ally, that means – If you say to me, I'm your ally, then I know that I get support from you, but you need to feel like on your issues, I'm an ally too."

One participant cautioned against making assumptions about who your allies are. The participant said, "Just because [the organization] serve[s] the deaf and hard of hearing, then [they] shouldn't automatically be [our] ally. They're not. Talk to the blind, they don't want to be with [us]. Now you would think they would be, right?"

The term ally was analyzed in greater depth by another participant, acknowledging an important theoretical consideration. The participant stated

When society has got enough issues that it creates this sense of we need to band together. And with allies, allies implies that the larger society is not. By the way, that's an acknowledgment, there's a problem here. In the society in general, there are certain people we can trust, or certain people we can call on, and the rest, what are they? Not allies. I guess they are either problems or they're just unaware.

Necessary Characteristics of an Ally. Several participants identified characteristics that were necessary characteristics of allies and potential allies. One participant asserted that it is essential for an ally:

To be able to get out of your self a bit. To be able to understand someone besides yourself. And in the case of physical disability I think it's a question of breaking societal norms. The beauty norm. Those kinds of expectations.

Another participant pleaded that an ally must

Value the individual with a disability just as we do anyone else. ... You've got to really believe that the person is important. You need to know where

they are coming from and what their aspirations are and then you need to be able to provide your services to help facilitate the individual achieving their goals.

The participant elaborated this point through a discussion of what people with disabilities want:

They want the same life that anybody does. They might want to be president of the PTA, or be involved in the model railroad society. They don't want to spend every minute of their lives thinking about, "I have a disability and ain't that awful." They want to lead a life. That's their aspiration. ... Once you begin to value them as unique individuals, not just as a presenting condition with a face on it and you get to know the individual, then I think you're on the way. ... That's the core to me, in terms of all the rest of us, allies or [whoever].

Participants also recognized respect and openness as important qualities in an ally. One participant proclaimed that allies must "be open to experience and open to differences."

Another participant said

Respect. I'm impressed when people acknowledge when they don't know everything and are willing to learn. I think it's a really important thing if we're around someone whose reality we haven't experienced ourselves – ask about it and shut the hell up and listen. It's not just asking, it's listening as well. It's being open to learn. It's being interested enough to honest to god learn something from someone else. That shows respect.

Actions of Allies. Participants discussed what an ally is in terms of actions, behaviors, and roles. Responses revealed three primary areas of allied action: bridge builder/facilitator, educator, and advocate. One participant shared a personal example of being a bridge builder. The participant, who was involved in a traumatic brain injury (TBI) program, stated, "I don't have a traumatic brain injury. And from 1992 on, I was identified with [the TBI program]." The participant continued, "I made it clear to people that I didn't have a TBI and ... that I wasn't an expert on TBI ... I was an expert in

bringing people together, to work together on impossible problems.” Similarly, another participant recalled an opportunity to help build a bridge between a local Independent Living Center (ILC) and the Department of Rehabilitation (DR). The participant shared

I feel like I actually got to do some promoting of the IL philosophy as a professional, in my relationship with DR. The DR has this interesting perception of the Independent Living Center. ... “They’re good people, but they don’t necessarily get a lot done. They’re better at the bigger picture of advocacy, but day to day, they don’t really help people change their lives that much.” DR never has felt like ILC was very good at helping them meet their goals. I really got to talk a lot about the independent living philosophy and why it is so important, and why their goals might be slightly different. I got to help kind of bridge that street crossing. Help [the ILC] understand DR more, and DR understand [the ILC] more.

Other participants responded to the importance of education and the role of the educator. One participant declared, “If people aren’t providing access to a whole segment of society, well, we need to educate them. We need to point this out to them and preferably, my philosophy is, do it nicely at first and go from there.” The third behavior that was revealed through participant interviews was the advocate. One participant commented on the importance of “supporting the values that people with disabilities have and live by.” Another participant said

I have a great deal of passion in fighting for the underdog and standing up for people whose rights are oppressed. Standing up for people, not necessarily being their voice, but standing alongside them as they fight for their rights. And along with folks, really looking at the systemic work. And making people, other agencies and services, accountable to [the disability] community. So, I’m very active. I see myself as an advocate and as an activist.

Who the allies are, or could be.

If we use the image of concentric circles, reaching as far out as possible, the family members [and] the professionals are close to the center. If we

define the center as the person with a disability or the population of people with disabilities - family members, close friends, professionals, we need them as allies.... People whose job puts them into contact with the public, may be another nice circle. We need them to know how to behave. To know enough to know how to behave and not to discriminate. And not treat people badly because of a disability. Then there's the general public.

Participants provided a broad range of ideas of who allies were and who allies could be, including those mentioned in the participant's comment above. Four categories of ally and potential ally emerged from the data. Participants most commonly referred to professional allies, followed by family allies. The third category included particular groups or organizations who could potentially be allies, and the final category acknowledged the potential for everyone to be an ally to the Independent Living Movement.

The most common ally discussed by study participants was professionals. Despite the prevalence of healthcare professionals in the lives of people with disabilities, there were different perspectives on their effectiveness as allies. One participant declared

In my belief, everybody in the health and human services field ought to be allies. That's what I teach.... I say, "You are needed. The Independent Living Movement needs you because in your life you will have an opportunity, everyday of your life to help promote independent living and choice." The more I realize it, it's a critical issue. It's [also] important to get people with disabilities into the helping professions. But, there aren't enough and so we need everybody. I don't care whether we are talking about somebody in a medical rehab program or voc rehab or a nursing home or wherever they are...their understanding of the principles of independent living is very important in facilitating people's independence.

Although described as important, alternative perspectives illustrated several challenges to allied relationships with professionals. Participants described the way that the predominant medical model limits empowering alliances, "It's the role of the medical

model, or healthcare professionals to fix people with disabilities and to teach them how to live within the normal world.” Another participant spoke of the medical model assumption of illness. The participant said, “To me, health has to do with sickness and I don’t relate disability to sickness necessarily. I mean, we all have doctors, we have dermatitis, or whatever comes up, like everybody else. They need healthcare like anybody else.” A further example was offered by a participant who shared a personal experience of how the medical model can limit the overall quality of life of a person with a disability. The quality of life of this participant’s son was influenced by a healthcare provider’s intense focus on the assumptions of the medical model:

Now, it had taken [my son] a year and a half to get out of the [iron] lung. There’s this big push [from the doctor], that you can’t keep him in the lung because he’d become dependent upon it. That sounds good to people who don’t need it to breathe. But, when you do, it makes a big difference. So, as soon as he went back in the lung his vital capacity increased, he got more oxygen in his blood, and he just improved.

Healthcare professionals were also discussed by participants in terms of professionalism and retaining negative attitudes towards people with disabilities. One participant commented that “there have been problems historically with healthcare professionals, only in attitude.” Another participant said specifically of rehabilitation professionals, that “they have been very slow to come to an understanding that people with severe disabilities can be independent citizens and work.” Similarly, an additional participant iterated, “Doctors don’t want to see people with disabilities.” The participant continued

How many doctors’ offices are actually accessible? Are there places in the waiting room where a person with a disability can get a place to sit? Is there space to maneuver a wheelchair? Most doctors don’t have adjustable

examining tables. How do you transfer a person from a wheelchair to an examining table if their chair is down here [gesturing to floor] and the table's up there [gesturing up] and you can't lower it? How do you examine a woman in a wheelchair for breast cancer? How do you do a mammogram, when you've got to be standing in front of the machine, and the machine doesn't come down to this height [gesturing at chest height, seated] to examine her? These are all things that doctors need to start putting into their offices to understand.

An additional barrier to alliances with healthcare professionals is, as one participant described it, "I know best in the medical profession. I know best. I'm the specialist. I will tell you what you need." Another participant referred to the assumptions and the effect of professionalism on allied relationships. This participant shared that many professionals are threatened by the critique of professionalism within the Independent Living Movement, "It feels like, 'my professionalism is undermined because my advice isn't valued.'" The participant continued by offering an alternative definition:

Professionalism is actually not about how many degrees you have, or how many classroom hours you've had; it's the extent to which you facilitate choice. That's professionalism. So, there's a need to redefine it. If you don't redefine it, it's a real stumbling block.

Participants discussed a third category of professional allies through encouraging and discouraging examples from their personal experiences. One participant shared the experience of a medical provider lamenting failure over the medical prognosis of the participant's son. The participant recalled

When I talked to the doctor, I said, "I am very glad that he lived." The doctor was pretty upset, and said, "How would you like to live the rest of your life in an iron lung? Have you ever been in one?" I said, "No." He said, "Well, I have, and it's not fun. It's terrible." And of course, this [doctor] was dealing with his feeling of being a failure as a medical person.

Participants also shared examples of encouraging relationships with professionals.

One participant shared an experience of literally watching attitudes and perceptions change among medical students:

[A friend] had access to these medical personnel by teaching social work classes. And he started to put lists up [for students] to visit both the Independent Living Center and our [university] program. So, he would invite these students to take this seminar and they would come over and they would visit the [university program] and the Independent Living Center, and then come over for dinner. And at dinner, they would come and sit [with] people in wheelchairs sitting on the other side of the table or wherever. They were eye level to eye level and they were allies and friends. They would see people in wheelchairs as people, rather than just a medical problem.

The same participant remarked on the crucial difference in experience when a professional has a positive attitude and has had positive experiences with people with disabilities. The participant declared, “I’ve taken quite a few people to the hospital ... and the times ... when they were in the hands of a medical person who knew what to do and not somebody who was terrified, makes all the difference in the world.”

Another participant revealed more practically-oriented benefits that a professional ally can provide:

I think, if you’re in a position where there is some respect attached, being a professor or a doctor, or whatever your title is, I think you can be very helpful as an advocate. The strong stipulation is that you have to be working with people and not for them. And that’s of course what the Independent Living Movement hates, is being worked for, advocated for. But, I think there is a position, a role for people ... who can use the authority that comes with being a professor or a doctor or some other professional, to write support letters, to make phone calls, to help access resources ... And also, just to help dispel stereotypes That’s a role that we can play.

In summary, the potential for allied relationships with professionals was discussed in-depth from diverse perspectives in this study. Participants identified challenges posed by the medical model of disability, the dangers of professionalism, and shared experiences of relationships with professionals.

Following the category of professional allies, was the category of families. Families were identified and discussed as a generalized category of allies or potential allies in the ILM. One participant said, “I think families are the greatest allies. That pretty much makes or breaks a person from the get go,” and, “Parents are really the unsung heroes because they do more work than is really recognized.” Another participant used an example to demonstrate how parental attitudes can effect a child with a disability. The participant said

Parents can be great allies and they can also be huge stumbling blocks. Parents who understand independence and everybody’s yearning for it, treat their children with disabilities very differently than do those for whom the only concern is safety and an easy life.

The participant went on to explain how lower expectations limit choice:

My wife teaches special education and last year she had a student with very severe physical disabilities but who had lots of potential and wanted to be a teacher. Over the course of many conversations she learned the girl was fully expecting not to go on to college and that she would need to move in to, at least a board and care facility, if not a nursing home, because that was the only way she could survive in the community. Her parents firmly believed that, and that was all she was aspiring to. One of the things my wife was able to do was to work with both the girl and her parents to help them understand that she had choices. She had options and opportunities. Which makes my wife an ally, doesn’t it?

Several participants also identified a third category of potential allies who were particular groups of people sharing similar obstacles and issues with people with

disabilities. Participants suggested that the shared experience of being marginalized by society could foster potential allied relationships. People who are aging and people who are poor were suggested as natural allies because they “basically have a lot of the same issues that we do. We want to control our own lives. So do they. And guess what? A lot of people are trying to take control.” Another participant stated, “I think any group of people who feels that they have been oppressed or mistreated could be an ally just in terms of talking of their experiences of how they’ve affected social change on a personal or bigger level.”

Political leaders and public decision makers were also identified as potential allies. One participant shared that “there are Senators [and] there are legislators who are allies. [It is] very important to cultivate those people too.” Similarly, another person commented on the lack of political representation by people with disabilities, further supporting the need for political allies. The participant said

People with disabilities don’t have a lot of political clout. We don’t vote, as a community. We are discouraged from voting. ... If you happen to be visually challenged. If you can’t read the ballot, try going to any of the polling places in the county and ask them for a magnifying glass. There are none. There are no Braille ballots. There are many polling places, we found several of them last year, that didn’t have wheelchair ramps.

The final category of who potential allies could be, was reflected by participants’ desire to extend the potential ally role to everyone. One participant had mentioned trying to generate a list of allies prior to the interview and recalled that the list “expanded so much. I didn’t know where to stop.”

In this category, participants shared all of the following types of people as potential allies: People who work in technology, businesses, community service

organization, personal care attendants, disability related organizations, peers, personal friends, academic personnel and instructors, and even strangers on the street.

Choosing Allies. Several participant responses alluded to the importance of choosing allies. One participant discussed a situation in which individuals defined themselves as allies, but the participant did not. Choosing allies was important to this participant whose example illustrates how not all potential “allies” are wanted or appreciated. The participant shared

When [our son] was first in the hospital, people would come around with their religious tracts and stand and preach to these kids because, of what I call, superstitions, or their strong beliefs that if somebody just has strong enough faith they’ll get up and walk. And this I find not very helpful and quite unrewarding to anybody involved. ... I don’t consider that being an ally, where, in their terms they would consider themselves [an ally], being that [they believed], “We have to save these people.”

Another participant, shared thoughts on choosing “a stranger on the street” as an ally. The participant said

A person with a disability that has savvy at all, gets really quick and smart about assessing, just by a quick look at somebody whether they would be willing to open the door. There’s a lot of people in the street that you won’t ask. Either because [they] look like somebody that you don’t want to talk to, or more likely, somebody that does not look like they’d be an ally. They don’t want to. They don’t want to be asked. Or maybe they even won’t. Or maybe they ignore you. All these things happen.

An additional example of importance of the concept of “choosing allies” was discussed in the context of both choosing and employing personal care attendants. A participant said

Attendants are your allies, and ... there has to be respect on both sides. The person with disabilities gets to make the decisions, but the attendant

can't feel like a slave. It's a very complex relationship, and when it works well, it's great.

Similarly, participants responded to whether or not the action of being chosen as an ally or choosing an ally needed to be initiated from within the Independent Living Movement. One participant response was specific to people without disabilities. This participant said, "I think since many of the problems are in the able-bodied community and their lack of understanding, I think it's very important that there be allies that are a part of that community and can help bridge people." Another participant considers educating the ILM about choosing allies. The participant pondered, "It's interesting, when I hear myself talking, I'm thinking, 'well, what does that mean? Do we have to go out and start educating people in the Independent Living Movement about how we can be their ally?'"

In summary, the participants provided vivid and articulate reflections on what an ally is, and who allies are, in the Independent Living Movement. Their comments included definitions of ally, necessary characteristics of allies, actions or behaviors of allies, who allies are or could be, and lastly, choosing allies.

Themes on Allies in the Independent Living Movement

Five broad themes emerged from the data relating to allies in the Independent Living Movement. The themes are: Commitment, Trust, Expectations/Assumptions, Leadership, and the Importance of Allies. Each of the five themes emerged as separate and distinct categories, but are closely related to one another.

Commitment

The commitment theme emerged as participants discussed the necessary time, energy, and dedication required to maintain active allies and alliances. Participants expressed this theme in terms of two differing levels of commitment. The first level of commitment shared by study participants was commitment at the organizational or movement level. A participant declared disappointment when stating that “in the absence of someone doing what I was doing, it sounds like the factions are reforming and it makes me very sad. Because it doesn’t happen automatically. That’s what I believe. It takes a lot of damn work.” Another participant related more specifically to maintaining what is already in existence; suggesting that “right now, we’re just trying to make it. Right now you can’t think about growth or creating new. You want to support the bridges that you have. They’re crumbling.” Yet another perspective recognized a fundamental challenge for the Independent Living Movement in that “it would require a lot of organizing and people within the ILM to get out there and ask – to ask for more help.”

Participants also shared various perceptions on being personally committed to allied relationships. One participant described a challenge at the family level; stating that “One of the hardest parts is not having time for yourself, the family unit. You don’t go lots of places, and by the end of the day, you’re exhausted.” Another participant described the individual commitment expected of people with disabilities who become employers, managing and organizing a team of personal care attendants. The participant

stated that “not all people with disabilities have an ability to manage a team of people and realize they’re an employer.”

Trust

Trust as a theme emerged as participants revealed a lack of trust within the Independent Living Movement of people without disabilities, professionals, and the greater society in general. One participant described a difficult personal experience and concluded, “I think, bottom line, that individual did not have a whole lot of trust of the able-bodied community in the first place.” Another participant attempted to determine which posed a greater threat to developing trust in an Independent Living Center (ILC): Being a professional, or being perceived as able-bodied. The participant contemplated

I feel like [the independent living] philosophy, makes it real hard for me to be an ally as a professional with a master’s degree. I feel like in the smaller picture, sitting in ILC staff meetings and meeting new people, me not having a visible disability makes it harder for me to be an ally.

Several participants referred to a generalized sense of lack of trust of people without disabilities, professionals, and society in general by many people with disabilities. A participant disclosed, “One thing I’ve noticed, in almost everyone I’ve met over the years, is a real hyper- sensitivity or a sensitivity to, ‘Who are you? Is this a pity trip?’” Another participant similarly commented on the lack of general trust and a relatively consistent feeling among people with disabilities that the independent living concept and opportunities could be stripped away by people without disabilities. The participant described the situation as “an underlying fear, and alertness. A yellow alert status. That’s where all of the suspicion is coming from. Those outsiders are going to take over, going to try to take over.”

Assumptions/Expectations

This theme includes a number of statements that alluded to various assumptions or expectations of being an ally. This theme is broken down into feeling comfortable, feeling welcomed, and feeling valued. The importance of feeling comfortable emerged from several participants who described uncomfortable situations or experiences in their involvement in the Independent Living Movement. Participants shared that there were situations in which they were “walking on eggshells” and “always being watched.” Other participants mentioned spending “a lot of time worrying” or being “scared” about their language so as to not inadvertently offend someone.

One participant recalled a situation in which feelings of being unwanted or unwelcome were illuminated. The participant shared a training experience while working at an Independent Living Center. The participant recalled

I was really singled out at that training. I was the only person in the room without a disability, in fact, the majority of people in the room had very visible disabilities. When the [trainer's] were speaking about the medical model or the rehab model, they would just immediately zoom in on me and I felt so singled out and so uncomfortable.

The participant continued by sharing feelings that resulted from the expectation of being wanted, welcomed, and liked as an ally, and as a person:

It was hard because I had heard a lot about the [trainers] and they were these amazing people that had done so much for the ILM and civil rights. And they had been around for so long and just professionally and personally, I totally wanted them to like me. I just wanted to be able to be friends with them and be able to kind of just tell them how much I respect them and love what they are doing. It was so awkward and so uncomfortable for me that I couldn't even do that. I kept trying. Okay, I'm going to bite my tongue, swallow my pride and thank them, and I felt like, if I did that, they would feel like I was being condescending to them, or patronizing. Oh, thanks, for the work that you do. You know? And so, I

just ended up not saying anything. And it was the most uncomfortable independent living experience I ever had.

Participant responses also suggested the challenge of feeling and being valued within allied relationships. A participant shared an experience in which “it was often an uphill effort to get some of my colleagues to value what I say, to treat me as a valued colleague” because the participant did not exactly fit into the expected category as an employee at an Independent Living Center. From a different perspective, the concept was also discussed through challenging the assumptions of the inherent “value” of being a professional. A participant said

You shouldn’t expect your advice to be valued because you are a professional. You should expect it to be of value because it’s good advice. And you should understand the difference between giving advice and making someone else’s life decisions for them. I think learning that can be very difficult for some.

The participant continued,

Doctors have probably been the hardest to persuade in this regard of any of the helping professions. Historically. ... I think it’s in the water at the med schools. [In] a doctor’s training, they spend very little time and attention on facilitating other people’s options. ... Doctors are great people, and we really need them. But, there is nothing, in my opinion, in [a] doctor’s training that prepares them to be allies.

Leadership

Leadership emerged as a very important theme. The majority of participants strongly asserted the importance of people with disabilities maintaining power through continued occupation of leadership and decision making positions in the Independent Living Movement. This category can be discussed in relationship to six sub-themes.

First, it was expressed that people with disabilities had more credibility as leaders. A participant commented, “There’s more credibility. Leaders. The public leaders, to be credible, need to be people with disabilities, who identify as people with disabilities, and can speak freely about it in cases not immediately obvious.”

Second, it was argued that people with disabilities, by law, are guaranteed leadership and control within federally funded Independent Living Centers.

The boards for Independent Living Centers, by law, have to be 51 percent people with disabilities, at least. Not that that makes them perfect, by a long shot. It doesn’t mean that people with disabilities are better qualified. But they are the people whose lives are being affected.

The third sub-theme iterated by participants is that successful outcomes in the movement itself require leadership by people with disabilities. One participant stated, “Within disability-related organizations, which is a mix of people with disabilities and not, the good ones are generally controlled by people with disabilities.” Another participant supported this assertion stating

All of the movements, the ones that have worked, every one that I know of and certainly the ones that I saw, were generated from disabled people. And it was completely a group effort of these people. It wasn’t an agency, a helping agency. They directed others. And I think if there is anything that is critical to the movement, it is that people direct their own lives.

The fourth sub-theme reveals inconsistencies that were reported among participants relating to the actual visibility of disability among movement leaders. One participant stated, “I think first and foremost, it’s image. If a person [doesn’t look disabled] that doesn’t mean I would exclude them, necessarily, but you have to be straightforward about it.” Another participant recalled, “I was asked at one point to be the director of the program, and I said, ‘Absolutely not.’ It needed to be someone with a

visible disability in that position. At that time it was very important to me.” The participant continued

They’re the people who got the idea. They’re the ones who put the program together. And I could be a supporter, an ally... but they had to be out in front. Raising funds and talking with other people in the university. This is who we are. This is what we’re doing.

An alternative view of the previously discussed “visibility of disability” addressed the present challenge of adequately and appropriately representing a diverse range of disabilities within the Independent Living Movement. In response to whether or not ILM leaders need to have visible disabilities, one participant stated

It used to be that way. I mean, if you can imagine that the major criteria be, for a leader of a state organization that they had to be a “quad,” or a “para.” It’s really interesting because ... here we are representing cross-disabilities, which includes people that don’t have visible disabilities, and we’re advocating for them, but, yet, we are discriminating against them within our own organization.

The fifth sub-theme is leadership development of people with disabilities. A participant imparted

I think that the focus is on recruitment of people with disabilities. Leadership development of people with disabilities. ... Getting the concept of independent living isn’t just a problem for people with[out] disabilities. There are lots of people who have disabilities that don’t [understand] independent living.

Another participant explained one of the challenges in developing a strong leadership base made up of people with disabilities:

Sometimes there aren’t enough trained people to do it, and there’s reasons for that. I think the level of education for people with disabilities is much lower in general. Right around here, there’s almost no excuse in the Bay Area. But there are a lot of areas where it’s not common.

The sixth and final sub-theme that emerged in the leadership theme was the role of people without disabilities. Participants tended to entirely reject the notion of people without disabilities occupying positions of leadership and power. “It would be like putting a white person in charge of a black group. It just isn’t done. And even so, there are quite a few non-disabled people running disabled organizations in this country.”

Another participant described the issue of people without disabilities climbing the corporate ladder of a disability-related organization as a “perplexing perplexity.” The participant stated, “I try to encourage people without disabilities to do a lot of things. And there are places for everybody. In the actual [movement] philosophy it’s very hard for the top person to be a person without a disability.” The participant continued

A lot of people without disabilities are running organizations and doing a reasonable job. So, it’s not like it doesn’t happen. Theoretically, it would be better if people with disabilities were doing it all. But, sometimes there aren’t enough trained people to do it. There’s reasons for that too. I think the level of education for people with disabilities is much lower in general.

Another participant responded personally when the initial challenges of working in an Independent Living Center were recalled. The participant said

One of the things that I ran into in the statewide association of Independent Living Center directors, was that there was a growing insistence that [the] principles of independent living demanded that [not] only people with disabilities be in charge of their own lives, but that they also be in charge of the programs that serve [them], and I didn’t fit into the category and so it was often an uphill stretch, or an uphill effort to get some of my colleagues to value what I say, to treat me as a valued colleague.

The Importance of Allies

The importance of allies emerged throughout data collection and analysis as a meaningful theme and an underlying factor in discussing the success of the Independent

Living Movement. The majority of participants shared the sentiment that allies were absolutely critical to the long term outcomes of the ILM, on both personal and movement levels, for several reasons. First, one participant expressed that on a personal level, a benefit for either being or having an ally is as simple as “just sharing information and getting to be human with people.” The same participant went on to explain that, on a movement level, allies are important in helping to change the “bigger picture.” The participant stated

On the bigger picture, a benefit of being an ally is social change. Changing the big perception that people with disabilities need to be cared for, and not, well, not looked down upon and pitied. “Oh, that poor guy in the wheelchair.” It seems so obvious that that needs to change. I think being an ally for anything that you believe in, it’s for bigger change.

Other participants echoed the importance of allies for the bigger picture of social change.

One participant used an analogy to illustrate the necessity of seeing a more “complete picture.” The participant shared

[The blind man] that touched the trunk said, ‘I think the whole elephant must be very much like a snake.’ Whatever part of the elephant that you encounter, you think that’s the elephant. But the elephant is much bigger. The whole elephant is a very different creature and that’s why we need each other. We need to know what that elephant really looks like before we can proceed. And also, it’s all too hard. Everything is too hard unless we work with each other. If we want to make changes. If people with disabilities are the only one’s going after “x” and if people with disabilities comprise 20% of the population, that means 80 percent of the population doesn’t give a shit. That means we’re never going to get what we want.

Other participants also remarked on the importance of allies for the purpose of having more people who understand and share the philosophy and goals of the ILM for example, “allies totally need to be welcomed only because it’s just more people to explain what IL

is and it's also people in different parts of society that are able to spread this information." A final area explored by one participant, and a fitting conclusion to this chapter, was the recognition, that it is easier to struggle together, rather than all alone:

It's one of the hardest parts of being a human being, if we feel isolated, alone. So, anything that overcomes that is a good thing. And when I work with someone, we give each other more energy and if we work together on something we often accomplish something neither one of us would have accomplished separately. Getting good ideas from each other. Energizing each other. Being less afraid to go out there and fight a battle. I mean, what person is going to be idiot enough to go off and fight a battle alone. It's scary enough to go out and fight a battle.

CHAPTER FIVE

Discussion

This chapter is divided into two sections. The first section provides a critique of the methodology of this study, including recruitment limitations, research design, reducing potential bias, and decisions regarding the presentation of results. The second section analyzes the results of interviews with participants in the Independent Living Movement (ILM). This section includes a discussion of defining allies, defining disability, a critical examination of the social model of disability, emerging theories and frameworks for defining disability, and an analysis of oppression and privilege as they relate to allied relationships, particularly in the ILM.

Methodology Critique

This study used qualitative research methods to explore the meaning and experience of being or having allies in the Independent Living Movement. Specifically, this study examined the unique challenges, contributions, risks, and benefits of being allies and having allies in this important social movement.

Recruitment Limitations

A purposive sampling strategy was utilized to produce diverse perspectives on the experience of being and having allies in the Independent Living Movement. Ten participants were recruited for the study, out of a total of 31 eligible potential participants. The researcher relied on three key informants to establish this diverse sampling pool.

A purposive sampling strategy has several limitations. The researcher identified three sampling limitations that pertain to this study. First, utilizing key informants may limit the potential participants to those who are known by the key informants. The researcher acquired the majority of the potential participants from one key informant in particular. To help address this limitation, two additional key informants were also recruited to provide additional leads to potential participants. The final sample of ten who participated in the study was a mixture of participants identified and recommended from all three key informants.

Second, purposive sampling is not representative and the results can not be extrapolated to the population as a whole. This research was conducted in the San Francisco Bay Area, in Northern California, and participant responses are not intended to represent the opinions of people in other geographic locations. However, the results may be transferable to other studies on allied relationships in social movements.

Third, there are known categories, or perspectives that were not included in this study. For example, due to time, resources, and access constraints, this sample did not include a person under the age of 18, a professional with a visible disability, or a person with a significant cognitive disability. Ultimately, these sampling limitations were known by the researcher and accepted in lieu of the rich and meaningful data that emerged from the sample that was established.

Research Limitations

Several limitations in the research design were identified before the study began. As previously discussed, the results are limited in generalizeability, as this study did not

attempt to understand the universal experience of being or having allies in the ILM. However, the study design, based on the conceptual framework of naturalistic inquiry, was more concerned with “understanding the richness and depth within one context and with the capacity to retain unique meanings that are lost when generalization is a goal” (DePoy & Gitlin, 1998, p.102). Additionally, while this study made efforts to include a diverse sample of individuals, it did not attempt to analyze racial, gender, sexual, or ethnic differences among participants in the ILM. A final limitation of the research design was the reliance on self-reported data, which inevitably contains potential inaccuracies due to an individual’s memory, differing interpretations of events, and varying communication styles.

Reducing Potential Bias: Trustworthiness and Credibility

Qualitative inquiry is primarily concerned with procuring a detailed description of the phenomenon in question. A key concern is confidence that the collected data and subsequent presentation of data were accurate reflections of the phenomenon. The researcher is responsible for taking steps to enhance confidence that the data do indeed reflect the reality of the phenomenon under question (DePoy & Gitlin, 1998). In this study, the researcher relied on four strategies to reduce potential biases and augment trustworthiness and credibility. These strategies included an interrater reliability test, peer debriefing, member checks, and reflexivity.

Interrater reliability. An interrater reliability test was used to compare the validity of the researcher’s coding scheme. The researcher involved a colleague who had knowledge of qualitative inquiry, and additionally, had experience working with people

with disabilities, but not the Independent Living Movement. Thirty percent of the reported data were coded and discussed by the independent rater and the researcher until consensual agreement was achieved. Initially, the independent rater agreed with 72% of the researcher's coding decisions. Through discussions that followed, the researcher was able to clarify several codes by combining two together and re-labeling another, which resulted in a follow up agreement of 100%.

Peer Debriefing. Peer debriefing is a strategy that utilizes an additional “external analyzer to function in the capacity of a co-investigator” (DePoy & Gitlin, 1998, p. 232), when there is only one researcher involved in the study. The purpose of peer debriefing is to evaluate the analytical process, which “provides an opportunity for the investigator to reflect on other possible competing interpretations” (p. 232). The researcher utilized two external analysts, professional and academic colleagues, and three San José State University faculty members who were serving on the researcher's thesis committee.

These external analysts provided multiple opportunities to debrief, re-evaluate, and modify interpretations of data throughout the course of data collection, analysis, and reporting. For example, the researcher utilized the writing process to clarify themes and substantiate the categories. Drafts were shared several times with thesis committee members, offering multiple opportunities to evaluate and debrief during data collection and analysis. All of the reviewers who read the emerging analysis asked clarifying questions engaging the researcher in a continuous critical analysis of the data. Peer debriefing provided a forum for the researcher to discuss the possible interpretations and

ultimately improve the overall clarity of the emerging themes and concepts from the study.

Member Checks. Member checks were used to review and identify the researcher's assumptions throughout data collection and analysis. Participant interviews and discussions with key informants provided opportunities to check assumptions and verify the researcher's interpretation of emerging themes and concepts. In addition to satisfying the recruitment needs for the study, conversations with key informants were particularly helpful in checking the validity of the researcher's interpretations from designing the research to presenting the data.

The feedback that was offered by the key informants was critical. For example, before data collection had begun, the investigator had been using the word "beneficiary" to describe people who could potentially benefit from the achievements of the Independent Living Movement. The informant warned the investigator that the word beneficiary, regardless of intention, could be received negatively by many people with disabilities. The researcher's intention was to describe the "allies" and the "other people who participate" in the Independent Living Movement, without simplifying the experience specifically to people without disabilities being allies to people with disabilities. The key informant cautioned

It's dangerous to make an inequality. I mean, to me, allies means, "We're equal." We're bringing different stuff and we need each other. Because of the sensitivity of the subject of people with disabilities considered less than, inferior to, excluded from, not normal ... There's a hypersensitivity to the inequality issue. Beneficiary is an inequality word. ... Beneficiary and benefit are clearly related linguistically, however the word benefit – people who benefit from – feels to me less offensive than the word

beneficiary. I think because beneficiary, to me, is just someone who is receiving. Not giving, just receiving.

The researcher accepted and appreciated the feedback and never used the word “beneficiary” to describe any of the study participants. Instead, the terms “having allies and being allies” and “allied relationships” were used, which significantly and appropriately re-framed the inquiry and the conversations with participants.

Reflexivity. Reflexivity is a process by which the researcher engages in continuous self-reflection to help determine how her own experiences and perspectives have shaped and influenced both what was learned, and how it was learned. DePoy & Gitlin (1998) argue that it is through reflection that “investigators evaluate how understanding and knowledge are developed within the context of their own thinking process” (p. 231). Throughout this investigation, the researcher kept a journal, which documented personal feelings, attitudes, and ideas that surfaced and emerged during the study. The journal was a particularly useful tool from which four key insights emerged: the research and researcher’s assumptions, the researcher’s identity, questioning the researcher’s identity, and the spirit of the research. Each of these key insights are briefly discussed below.

First, prior to the onset of data collection, the researcher identified several assumptions related to this study.

1. Participants would be truthful and honest to the best of their knowledge and ability.
2. Participants have had invaluable experiences and insider knowledge that they would share with the researcher.

3. There would be differences of opinion among participants in general, but more so among those who have longer histories or more experience in the Independent Living Movement.

4. There were many allies within the Independent Living Movement, and their experiences are largely positive.

5. Allied relationships are complex and can not be simplified to the binary: “People with disabilities *have* allies and people without disabilities *are* allies.”

6. The researcher would be able to recruit and interview at least ten participants representing diverse experiences of being and having allies.

7. The researcher would be able to gain access to participants and create a trustful, respectful, and comfortable environment.

8. The researcher would be able to obtain invaluable information on allies and analyze the data appropriately.

9. The research process and results will have the ability to impact future allied relationships in other social movements.

One key assumption was not recognized by the researcher, however, until completing data collection and most of the analysis. The researcher had assumed that all participants would share similar conceptualizations of the Independent Living Movement. It is unknown whether or not this assumption is correct, because the researcher failed to ask all participants to define the Independent Living Movement. However, reflections on interview responses suggested that there may be different perceptions of the movement and its underlying goals. This assumption was identified through reflective journaling.

Second, the researcher's identity became a source of dialogue, questioning, and reflection. Lack of trust and feelings of unwanted participation are documented in the literature as inherent challenges that researchers without, or perceived to be without, disabilities may encounter when their research topics relate to people with disabilities. One potential reason academia and researchers are met with such challenges is that the research related to people with disabilities generally adopts a medical model perspective, which continues to perpetuate the oppression and discrimination of people with disabilities (Bricher, 2000). Continuous self-reflection was particularly important in this research because the researcher does not presently have a visible disability, and is currently not directly involved in the Independent Living Movement. As a result, the researcher needed to build trust and credibility to gain access to the community. This was especially challenging given the prevalence of skepticism and lack of trust of professionals, researchers, and people without disabilities by many people with disabilities.

Many theorists, academics, and people with disabilities believe that only people with disabilities should participate in the research of people with disabilities (Branfield, 1999; Reindall, 1995). However, other researchers argue the importance of looking at the experience of disability from a variety of perspectives, which may include those of people without disabilities (Reindall, 1995). Gillian Bricher (2000) argues that non-disabled researchers who are engaged in research with people with disabilities need to take steps to ensure sensitivity, incorporate the social model and independent living, and find disabled allies. It is also argued that what is really most important is the purpose of

the research and the types of questions that are being asked (Duster, 1987). Troy Duster, relating to researchers who study people of a different race, eloquently stated that “we need to raise the kinds of questions that will force us as a nation, to see the gulf between the races anew, with fresh vision and insight” (p. 12). Those who are engaged in studies pertaining to people with disabilities have a similar opportunity to ask the questions that force everyone to look at the differing experiences of people with and people without disabilities, with fresh rigor and insight. This research was dedicated to that purpose.

A third key insight offered by reflexive journaling was analyzing thoughts relating to the researcher’s identity being questioned. Participants in this study implied a constant question, or curiosity, around the question of whether an individual has a disability, or identifies as a person with a disability. One participant said, “I think there’s always a question. ‘Does she have a disability? Is it invisible? Am I just not seeing it?’” Upon reflecting on these responses, the researcher recognized that no participants had inquired about her own disability status. The researcher was surprised, given the prevalence of participant responses that identified a perpetual suspicion over whether or not someone had a disability and the subsequent distrust of people who appear to be without them.

The researcher, through journaling and self-reflection, determined several possible reasons for participants’ lack of inquiry about her own disability status. Participants may have assumed that the researcher did not have significant impairments, perhaps due to their own perceptions or possibly the researcher’s lack of immediate self-disclosure. As indicated in the results of this study, self-disclosure, or identifying as a

person with a disability, is generally expected if the disability is not visible. It is also possible that participants may have asked or been notified of the researcher's disability status by a key informant known to both. In one case, a participant referred to the study by a key informant had previously met the researcher, and may have assumed from that interaction that the researcher did not identify as having any current impairments or disabilities.

The fourth key insight identified through the process of self-reflection informed the spirit of this research. This investigation was motivated by passion for establishing respectful alliances and social change. The researcher designed a study that incorporated the assumptions of the social model of disability from inception to presentation. For example, it was important to the researcher that the study design did not appear in any way to represent or reflect the individual-deficit focus of the medical model. This research adopted a theoretical definition of disability from the social model and focused on individual assets and the social deficits that limit an individual's access to community participation. The researcher utilized several allies to help gain access and credibility in the disability community. Finally, the researcher made a sincere effort to ask thoughtful and provocative questions which could help lead to a better understanding of the allied experiences in the Independent Living Movement.

Reporting Decisions

All researchers must choose how to best represent and report the data. Most often, qualitative data reporting includes terms which describe the participant characteristics, such as gender, age, race, or, with disability studies, disability type or

status. However, in this particular study, the researcher made a conscious decision not to identify participant characteristics, particularly disability status, in either data analysis or reporting. This decision was based on the researcher's concern with categorical thinking, along with the effects of oppositional terms, such as dis-abled versus abled, discussed in detail later in this chapter. The researcher also felt that not identifying participant characteristics would allow a sharper focus on the data's emerging concepts and themes.

The researcher's priority was to explore and recount the key concepts that emerged through this study from a variety of participant perspectives representing people with and people without disabilities, but not necessarily a comparison between the perspectives of those two groups. Peer debriefing, including thesis committee responses, challenged the researcher on the validity and reasons for this somewhat unusual choice. However, the decision not to report disability status was consistent with the study's objectives and broader goals. As a result, themes and sub-themes are reported without ability, or disability, attribution.

Analysis of Results

This section discusses key points related to the concept of allies and the Independent Living Movement. From participant accounts and their underlying themes, an emerging discourse on disability became evident. This discourse includes defining allies, defining disability, critique of the social model of disability, emerging theories and frameworks, and recognizing oppression and privilege.

Defining Allies

Study participants generally defined allies in similar terms. For example, an ally was defined as “somebody who can be counted on to support, advocate for and with a group of people about whom they feel strongly or with whom they identify [with] on some level,” or “an ally is someone that shares a philosophy.” Participants devoted little time to defining ally, but considerable attention to discussions of who allies were. Four different types of “ally” were identified and discussed by participants: (a) professionals, (b) family, (c) other groups of people, and (d) everyone. The majority of participants acknowledged a fundamental importance of having family allies, identified other groups of people who could potentially be allies, and shared the desire that everyone could be an ally. However, every participant spoke at length about professionals, sharing insights on both necessity and challenges with being and having professional allies in the ILM.

The results of this study demonstrate key characteristics that can foster or impede the formation of an allied relationship. For example, the intimacy of family generates a closeness that can foster the development an allied relationship. Conversely, professionals have significant disadvantages. Despite the necessity, allied relationships with healthcare professionals are often impeded due to historical discrimination, the influence of the medical model, negative attitudes towards people with disabilities, and professionalism.

Defining Disability

The literature review and the results of this study show that defining disability is clearly a challenge. Academics, activists, and participants in disability rights

organizations and movements rarely define disability consistently. For example, in this study, disability was defined by participants as individual deficits and as socially influenced.

There are, however, consequences of not defining disability. On a practical level, the way that disability is defined affects an individual's access to programs, services, and goods. For example, an individual may be granted the civil rights protections of the Americans with Disabilities Act, but may not be eligible for Social Security benefits. On a broader level, without an accurate understanding or consensual definition of what disability is, the Independent Living Movement, their allies, and observers can not appropriately and accurately identify, discuss, and address the "problems" that affect people with disabilities.

From a public health perspective, the problem of not having a consistent definition of disability affects the primary public health activities of assessment and surveillance. Public health identifies problems, challenges, or barriers to optimum health within specific populations of people; gathers data and information on the identified problems; determines a mode of action; and evaluates the progress (Institute of Medicine, 1988). Ultimately, inaccurate or unrepresentative definitions impede the public health potential to work as effective allies in a movement for social justice for people with disabilities.

In Chapter Two, the medical and social models of disability were presented and discussed in detail as two of the dominant perspectives defining disability. The medical model emphasizes an individual's deficit, weakness, or responsibility to adapt to the

environment. Conversely, the social model of disability changes the paradigm through which disability is understood by arguing that “disability” is created by social and physical environments which limit opportunities and access to community and social participation by people with impairments. The research questions and research design were based on the assumptions of the social model of disability. The study incorporated the social model’s conceptual definition of disability as “...the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers” (Finkelstein, et al, 1993, p. 28). It was assumed that participants, all involved in the Independent Living Movement, would share this social perspective.

Participant responses, however, tended to be rooted in more individualistic terms. Their definitions of disability confirmed that the medical model remains the dominant ideology for describing people with disabilities, even among people with disabilities, allies, and ILM activists. While the social model has been at the forefront of disability rights agendas and the emerging discipline of disability studies, it has been slow to change deeply rooted popular meanings. This striking contrast encouraged the researcher to revisit the literature for current criticisms of the social model and emerging trends in defining disability.

Criticisms of the Social Model of Disability

This study adopted the social model of disability as the framework for understanding and communicating respectfully and appropriately with Independent Living Movement participants and within disability culture. This social model posits that

“disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment” (WHO, 2001, p. 21).

The social model of disability assumes that it is the civil right of people with disabilities to participate equally in society, and argues that the medical model of disability fragments the human experience and fails to recognize the abilities of people who are defined solely by medical a diagnosis. Furthermore, the social model asserts that the language used to describe disability and people with disabilities within the medical model generates low self esteem, internalized discrimination, and decreased feelings of self worth, while simultaneously enforcing cultural and political attitudes and norms devaluing people with disabilities (Charlton, 2000). Despite the critical analysis that follows, the social model of disability, as an alternative to the medical model, was a valuable and necessary framework for this study.

Four current criticisms of the social model of disability were identified in this post-analysis literature review: (a) the model does not account for a sociology of impairment, (b) the language remains rooted in the medical model, (c) it is grounded in dichotomies, and (d) it relies on a unified identity. Each of these criticisms is briefly described below.

Sociology of impairment. Social models of disability argue that the term disability is socially constructed. The social model clearly distinguishes between disability and impairment, with disability representing the social imposition and impairment recognizing the physical, cognitive, or psychological condition. The social model of disability is criticized because of its failure to acknowledge the social

construction of impairment, or engage in a sociological analysis of impairment (Abberley, 1987; Hughes, 1999; Neath, 1997). Similarly, the social model has also failed to consider the sociological critiques of modernity, which argue that the “body” is itself a social construct (Abberley). Proponents of a sociology of impairment argue that this approach is fundamentally important because it encourages dialogue currently missing from the social construction of disability.

A sociological analysis of impairment yields three primary paths of discussion. One path needs to analyze the perception of people with disabilities from the viewpoint of the “non-disabled” (Hughes, 1999). As argued by Hughes, “It’s not the impaired body that is distorted, but rather the specular experience and the language that constructs it” (p. 165). Throughout this study, the researcher had multiple experiences that support Hughes’ argument. For example, the researcher was keen to notice the reactions, responses, and gazes that result from the “specular experience,” or encountering a person with a disability. A participant response from this study further supports Hughes’ assertion. The participant said

There’s a lot of people in the street that you won’t ask [for help]. Either because [they] look like somebody that you don’t want to talk to, or more likely, somebody that does not look like they’d be an ally. They don’t want to. They don’t want to be asked. Or maybe they even won’t. Or maybe they ignore you. All these things happen.

Second, a sociology of impairment would force a discussion of the body into the broader analysis of the social construction of disability. From this perspective, and similar to many feminist accounts, the body is defined as the site of oppression (Abberley, 1987; Samuels, 2002). Conceptualized this way, the body becomes the source

of the binary definitions, such as: normal versus abnormal, abled versus disabled, which label and prejudice people with disabilities. One participant in this study commented on the need to change social norms such as the beauty myth, implying that the beautiful body which is depicted as the social norm or desire is difficult to achieve. Furthermore, the medicalization of the impaired part of the body helps shape perceptions of people without disabilities, so that “the impaired person becomes synonymous with the condition (Hughes, 1999, p.165)”. In this study, the participant who recalled the woman who could not walk across the street fast enough offers a vivid example of this conceptual transfer. The participant recalled a physician telling the woman without a visible disability, “Carry a cane. That should make an obvious sign that this is something,” effectively making the disability an obvious characteristic, synonymous with the woman.

A third path of discussion suggested by a sociology of impairment emerged during analysis of the data from this study. As the researcher listened to participant accounts, engaged in reflective journaling, and discussed the emerging concepts with peers, it became apparent that dialogue around the meaning of prevention of impairment is imperative for public health professionals. Disability theorist Paul Abberly (1987) has long argued that one can both assert the value of people with impairments, while simultaneously promoting the prevention of impairment. However, theoretically, the debate between promoting and preventing is more complex, and many questions that are raised need to be discussed openly and across disciplines.

On a practical level, a good example illustrating the perspectives of preventing impairment was a drunk driving prevention campaign of the national MADD (Mother’s

Against Drunk Driving) organization. The researcher saw a poster for the campaign in May 2003 on the wall of a junior college cafeteria. The black and white poster showed a silhouetted image of a young person in a wheelchair. The caption read: "You don't want to end up like this." The message was intended to prevent drunk driving related accidents among youth. However, the message also clearly revealed that life was not worth living in a wheelchair. It is imperative that public health professionals consider the consequences of the meanings and interpretations of prevention messages to avoid misrepresenting and perpetuating negative attitudes and stereotypes toward people with disabilities.

On a larger, more abstract level, there are many questions regarding health, choice, and medical ethics that are intimately related to the concept of preventing disability. The following series of questions exemplify some of the pressing inquiries being raised. Who has the right to be born? Which forms of disability would be okay to birth and which should be aborted? If abortion was recommended, and one chose not to abort, would the parent lose social support? (Breckenridge & Vogler, 2001). Who has the right to choose to live or die? If a person is considered to be cognitively unable to make such a decision, whose right is it to decide? Whose choice is it to undergo major medical testing and/or treatment to attempt to cure a medical condition? What are the alternatives? Where are the positive images and life stories and experiences of people with disabilities living high quality lives? Is the goal of medicine to create and maintain a population of people whose health never changes? A population of people who are medically the same? Is preventing impairment the same as eliminating disability?

Where are the lines drawn between eugenics and good public health? These questions arise from a sociology of impairment and warrant deeper discussion within the social model of disability and public health.

Language. A second criticism of the social model of disability is that it incorporates the same negative language as the medical model. Author Steven Smith (2001) argues that the language in both the social and medical models is striving for “normalcy.” For both, “independence becomes the main aim” (Smith, p. 586) and people with disabilities having the opportunity to participate in the non-disabled world is the shared goal of each model. Similarly, Christopher Donoghue (2003) asserts that the biggest victory for American disability rights activists, the Americans with Disabilities Act (ADA), is rooted in individualistic, functional terms, rather than in the social terms of the social model of disability. Data from this study were similarly rooted in individualistic, medical model terms. For example, a definition of disability offered by a participant was, “...functional limitations that require some sort of adjustment or accommodation on the part of the individual.” Other individually-oriented definitions were also common.

Grounded in dichotomies. A further criticism of the social model is that it remains grounded in dichotomies; binary categories that perpetuate the discrimination and oppression of people with disabilities. This criticism argues that social theories of disability continue to dichotomize health and illness, normal and abnormal, able versus disable (Corker, 1999; Humphrey, 2000; Kaplan, 1995). It is also argued that such rigid binary thinking does not allow for the reality of changing and fluctuating abilities

(Corker, 1999). In this study, participant interviews revealed multiple binary categories that are imposed on people with disabilities. Five of these categories will be discussed in greater detail later in this chapter.

Identity. A final criticism of the social model of disability is its reliance on people identifying as having a disability. To gain strength, the social model must promote a widespread and strong identity among participants (Dowse, 2001). Results from this study confirm the identity focus of the ILM with participant comments such as the expectation of self disclosure when disability is not obvious or apparent.

Throughout this study, both through interviews with participants and conversations with peers and key informants, the researcher has come to believe that the absence of a popular understanding of what disability is creates a problem in accurately identifying people with disabilities. The identity issue is further complicated by an overwhelming perception of negative stigma attached to the term, so much that people do not want to be identified as disabled. For example, as reported in Chapter 4, many people who are aging share similar problems with people with disabilities, but do not consider themselves “disabled.”

Through the data collection and analysis of this study, the researcher came to believe that a social movement based on identity, such as the Independent Living Movement, is inherently challenged by these issues. It is difficult to build a strong movement based on a population which can not be effectively identified, or with people who reject the identity based on social stereotypes. John Anner, in his book *Identity Politics* (1996), says, “The premise of identity politics is that all members of the group

have more in common than the members have with anyone outside of the group” (p. 9). According to Anner, identity-based movements, in general, face inherent problems and challenges. For example, “It becomes harder to sustain the fiction that we all have the same problem when some members of the group are clearly doing a lot better than others” (p. 9). Ultimately, identity as the central unifying factor is weakened by people with multiple marginalized identities and plural social justice agendas, and by the exclusion of potentially widespread, diverse support.

While the social model of disability remains preferable to the medical model, the social model must address the questions raised by the excluded sociology of impairment, the negative and dichotomous language, and the problems associated with an identity movement.

Emerging Theories/Frameworks for Defining Disability

New conceptualizations of disability are arising in a variety of arenas. Similar to the social model of disability, they fundamentally reject the medical model. A variety of these alternative conceptualizations of disability were identified in the literature and this study. For example, in the literature, there were thoughtful and engaging arguments for defining disability from human rights (Schriner, 2001), multicultural (Gilson & DePoy, 2000), empowerment (Block, Balcazar, & Keys, 2002), and systems perspectives (Michailakis, 2003). Additionally, there were several compelling arguments for a feminist analysis of disability, extending the concept of patriarchy and power to disability inequalities (Neith, 1997; Priestley, 1998; Sheldon, 1999). Among all of the emerging

trends identified in the literature, however, a post-structural analysis is particularly resonant within the themes and findings of this study.

Post-structuralism is a theoretical approach that arose out of criticism of modernity and rejects the validity of binary categories that are imposed on people. Post-structuralism contends that categories and meanings are plural, unstable, and exist in relationship to other meanings and experiences. Feminists utilized post-structural thought to analyze the plural experiences of women, helping to dispell the limitations and constraints imposed on women through defining women in opposition to men. A post-structural view of women recognizes and honors the diversity of women, their experiences, and their choices.

Similarly, a post-structural analysis exposes the power structures within disability discourse. Power, from this perspective, is actualized through language and establishes the norm, which constitutes the truthful reality. A useful tool within the post-structural framework is deconstruction, which specifically focuses on the roots of power within language. Deconstructing the inherent power structures in the language that is used to describe disability exposes the dominant binaries that dwell in many of the models defining disability. It also illuminates the role and significance of binaries in the experiences recounted by participants in this study.

Binary Thinking. Binary thinking is problematic because it divides the world into two discrete boxes. A binary is not a simple opposition because the opposing terms are not equal; rather the two terms are dependent upon one another. One term will always be held in a position of higher power, or dominance, and the second term will always be

inferior, lacking the qualities of the first term. The binary exists to privilege the dominant term, which is the priority. Essentially, binaries construct a normative power of domination. An inherent problem with such thinking is that people often mistake the predetermined categories as an accurate and truthful reality (Kaplan, 1995).

This study confirms that binary thinking continues to greatly affect the way we conceptualize people with disabilities and the “problem” of disability. A number of binaries were evidenced in this study through the emerging discourses on disability, independent living, and allies. Key binaries, each of which will be discussed below, include, normal versus abnormal, health versus illness, independent versus dependent, visible versus invisible, repair versus impair, and able versus disable.

Normal versus Abnormal. Maintaining a strong binary between normal and abnormal is crucial in reinforcing power over people with disabilities. The prevalence of this binary is widespread and continues to be internalized in many definitions of disability. For example, one participant stated “Disability to me is something beyond the ordinary. We expect people to have two arms and two legs and nose and mouth and see and hear and walk and that seems to be the expectation.” Binary thinking clearly defined “normal,” and disability as “something beyond.”

The normal versus abnormal binary includes many nested meanings, such as, a normal person is a social contributor; financially secure; hard working: either has or desires a family; is healthy, strong, beautiful, and was raised to believe that anything could be accomplished with dedication. One participant in this study acknowledged the

prevalence of this social normalization, particularly around beauty, defining disability as “a question of breaking societal norms.”

Health versus Illness. A second prevalent binary is the common assumption that people with disabilities are sick, necessarily categorizing them into the opposing “not healthy” category. The negative connotation of sickness or illness is clearly evident when other words used to describe sickness, or illness, include feeble, broken down, confined, peaked, imperfect, suffering. People with disabilities, regardless of their current health status, are generally perceived to be ill. Thus, many people with disabilities are constantly subjected to the negative construction of sickness. A participant in this study spoke at length against this binary, stating

Health has to do with sickness and I don't relate disability to sickness necessarily. I mean, we all have doctors and we have ya know, dermatitis or whatever that comes up, like everybody else. But, I don't think it's right to equate the disability movement with the health movement. They need healthcare like anybody else.

Independent versus dependent. A third binary that plays an important role in conceptualizing people with disabilities is independent versus dependent. Dependence is powerless, in opposition to independence. Independence represents personal power, autonomy, self-reliance, and self-sufficiency. In contrast, dependence connotes need and is exemplified through terms such as subservient, helpless, and vulnerable. People with disabilities are often perceived to be dependent upon others. This notion is exacerbated when independence emphasizes self-sufficiency, placing the opposing dependent at the mercy and pity of others.

Within the Independent Living Movement, the hierarchical term “independence” is emphasized as choice and self-control, rather than self-sufficiency. Similarly however, the ILM also rejects the negativity of language used to describe dependence. This emphasis on self-control and choice is clearly evidenced in the definitions offered through this study. One participant articulated the subtle differences:

In the popular meaning, [independent living] means that you can do everything for yourself. Independent living, in terms of disability, means that you get to decide. You might not be able to do it for yourself, but at least you can choose the people who help you or choose the way you are going to get it done.

Visible versus Invisible. One important way of analyzing this binary through the Independent Living Movement is to question whether people with visible disabilities are granted more hierarchical power than people with invisible disabilities. People with visible disabilities have endured a different history of discrimination based on the visibility of their disabilities by dominant culture. Conversely, many people with invisible disabilities have been in situations where they are capable of “passing” on the scale of visibility and are perceived non-disabled.

Several participants commented in one way or another about this acknowledged hierarchy, referred to as “points” awarded by other people with disabilities. One participant asserted, “If you [had] the most significant [visible disabilities] then you had the most points. If you didn’t have a visible disability then you didn’t have the same power.” Similarly, in comparison to someone with a physical disability, another participant recalled that

Even after I started identifying myself as a person with a disability, I still didn’t get as many points as they did. In their criteria. Because, those of

us with hidden disabilities, we can pass. We can pass for regular people, at times, and they can never, and so there's an anger against us as well.

The phenomenon, being able to pass, is an important consideration because it is perceived that there is an additional source of power residing in this ambiguity. People with invisible disabilities have the option to choose when they will identify as disabled, and when they will not. This ambiguous identity is also present in the movement for gay rights, as some Gays and Lesbians are not visibly obvious. The complexity of this visible versus invisible binary poses particular challenges to the potential ally relationship because people who can not or choose not to hide their disability, or sexual orientation, are faced with the constant and continuous responsibility of defending their civil rights. Whereas, the individual who chooses when to be “visible” and when to be “invisible” may also be choosing when and in what situations to defend civil rights. Although allies share a similar position of luxury and privilege, allies must choose to be allies all of the time, not only when it is convenient or easy.

Repair versus Impair. An additional binary commonly applied to people with disabilities is repair versus impair. To be impaired is to be in a less than perfect condition, defective, or of diminished value or quality. Conversely, to be repaired is to be restored to a good condition, fixed, or cured. Within the medical model, extraordinary positive value is attached to the power to repair. This inevitably influences the perspectives, real or perceived, of health professionals. This binary emerged in many participant comments about health-care professionals and the medical model promoting a cure, or their responsibility to fix the impaired. One participant shared an experience in which, unable to eradicate the impairment of the participant's child, the doctor expressed

literal feelings of inadequacy and failure. The participant said, “When I talked to the doctor, I said, ‘I am very glad that he lived’. The doctor was pretty upset, and said, ‘How would you like to live the rest of your life in an iron lung?’”

Able versus disable. The able versus disable binary is perhaps the most prevalent in the context of people with disabilities. This dichotomy is of fundamental importance in a critique of disability discourse. To be dis-abled is first and foremost to be not able, to be not fit, competent, bright, adept, strong, or worthy. Dis-abled is to be wrong, deviant, incapable, incapacitated, a malfunction of what is normally expected. In contrast, to be able is to have power and skill, to be fit, to be worthy and efficient, and certainly to have a strong sound able-body. A necessary expansion of this binary extends consideration to individuals, the person with or without a disability.

The dichotomy, people without disabilities versus people with disabilities, attempts to accurately categorize people based on ability, as either able or not able. A rigid binary with pre-determined social meanings does not effectively accommodate the multiple definitions of disability that are adopted by a variety of perspectives. Moreover, this binary does not allow for the fluidity or variation of the human condition, and does not reflect the possibility that a person without a disability may become disabled.

Another aspect of this binary, argued by researcher Jill Humphrey (2000), is that these categories do not allow for practical or political space that encourages supporters, or allies, to organize in support of social change. For example, the women’s movement has called for male support of feminist efforts, and similarly, the Gay & Lesbian movement has called for straight allies to support efforts for social change and an end to

homophobia (Humphrey). The binary does not work in the more fluid and less visible world of disability. As a result, the prevalent dichotomy that categories people as able or not also diminishes the “theoretical-political space to differentiate actual and potential allies and enemies” (Humphrey, p.70).

The final point of discussion, which was one of the current criticisms of the social model that was discussed earlier in the chapter, is failure of the social model to analyze the body. Recognizing that all of the binaries discussed take place in relationship to the human body, this researcher believes it is of fundamental importance to critically analyze the conceptualization of the body. Feminist theory has effectively politicized the female body and raised consciousness over the inherent social demands that place illogical and unachievable demands on a woman’s body, and by extension, the socially constructed category of women. Disability must similarly politicize and theorize the body. The disabled body is medicalized. Rather than being viewed in terms of inherent strength and beauty, the disabled body is conceived of and visually related to as unattractive, disfigured, or deformed. The medicalized body becomes a source of public treatment by which the expertise of others is valued over the individual life within.

Analysis of Privilege and Oppression

Binary thinking illustrated how one term occupies a distinct and privileged position of power over the other. Power and privilege are associated with discrimination and sustaining the domination of people with disabilities through the medicalization of the body and a skewed perception of people with disabilities having little social value and high social burden. The disadvantages and discrimination that people with disabilities

face in this society illustrate the ways in which this group of people are oppressed by social norms, values, and practices rooted in binary thinking. Oppression and privilege emerged through the data in direct and indirect ways. Each clearly affects the lives of people with disabilities and the alliances that are formed. Oppression and privilege are discussed in greater detail below.

Oppression. The literature supports a conviction that people with disabilities have been subject to a history of oppression. Not all disability scholars argue that people with disabilities are an oppressed minority (Batavia, 2001), but most acknowledge the influence of oppression when identifying the roots of the problems experienced by people with disabilities. Three levels of oppression that have been used in discussions relating to other marginalized populations are institutional, cultural, and internalized. Through this research process it became important to analyze these levels in relation to disability illustrating the pervasiveness of oppression at each level and the impact on allied relationships.

First, institutional oppression is considered to be “differential access to goods, services and opportunities of society” (Jones, C. P., 2000, p.1212). In an article on racial oppression, Jones (2000) argued that changing institutional oppression is important because it maintains oppression by reinforcing social norms through systems and institutions. Jones discussed this level in two ways, through material conditions and access to power, both resulting in differential access to goods, services, and opportunities.

People with disabilities are subjected to institutionalized oppression through unequal access to power and material conditions. In this study, participant responses

suggested that people with disabilities have different, unequal access to employment, education, medical treatment, housing, community living and independent living opportunities, and structural/literal access to both public and private buildings and services.

In a culture that values labor, people with disabilities are routinely denied opportunities to contribute to a capitalist society, effectively diminishing an individual's worth. Frustrated, one study participant questioned, "What about being sure that people with disabilities, even though they have them, still get a chance at gosh, at least a public education. Get a chance at being able to be considered for employment?" In addition, receiving social service benefits while working, or in the process of returning to work, is a significant challenge. Many people with disabilities have few incentives, or are outright denied the opportunity to work, even partially, because it may put them at a risk of losing absolutely necessary social support and services.

Participants shared their beliefs that people with disabilities are less likely to finish high school or attend college. One participant expressed, "I think the level of education for people with disabilities is much lower in general." People with disabilities are still denied access to public and private structures, including many homes and businesses, despite the 1990 passage of the Americans with Disabilities Act. Another study participant identified and discussed the problem of people with disabilities being disproportionately under-served in the areas of health screening, disease prevention, and standard health-care. The participant pondered

How do you transfer a person from a wheelchair to an examining table if their chair is down here [gesturing to floor] and the table's up there

[gesturing up] and you can't lower it. How do you examine a woman in a wheelchair for breast cancer? How do you do a mammogram, when you've got to be standing in front of the machine, and the machine doesn't come down to this height [gesturing at chest height, seated] to examine her. These are all things that doctors need to start putting into their offices to understand. The dentist office is the same way. People with disabilities need medical care. It's hard to find.

Furthermore, the data suggest that people with disabilities are subject to unequal access to information, resources, and political representation. For example, people with disabilities are systematically denied access to political representation through inaccessible voting methods. Noting the lack of "political clout" of people with disabilities, one participant shared

We don't vote, as a community. We are discouraged from voting. ... If you happen to be visually challenged. If you can't read the ballot, try to going to any of the polling places in the county and ask them for a magnifying glass. There are none. There are no Braille ballots. There are many polling places, we found several of them last year that didn't have wheelchair ramps.

It is clear that with such widespread institutional oppression, allies can be of great help in changing the systems that place people with disabilities at such powerful and interrelated social disadvantages.

The second level of oppression, personally mediated oppression, or cultural oppression, is described by Jones (2000) as prejudice and discrimination. Clearly evidenced in the literature and condoned by social norms, people with disabilities are routinely subjected to prejudicial attitudes, ideas, and discriminatory practices. Examples include the dehumanization of people with disabilities, such as authoritative medical treatment, forced sterilization practices, a focus on the cure and return to normalcy, and avoidance, pity, and overall lack of respect. It is widely documented that

people with disabilities feel isolated and left out in their own communities. One participant in this study spoke of this isolation, “People with disabilities are still, as the ADA preamble language describes us, a discrete and insular minority. People don’t know us.” The participant also noted another kind of dehumanization, evidenced in increased visibility in the media explaining that “they’ve begun to see more physically disabled people in commercials – woo woo – identifying – yes, they have money, therefore they’re a market, therefore you cater to that.” But, another participant realistically noted, “There’s the dream some day that disability will be less stigmatized. I don’t know that it’s happening. I have my doubts. Even though we’ve made some progress, I don’t think there’s a whole lot of attitudinal change.”

Prejudicial and discriminatory attitudes toward people with disabilities are reinforced in the American popular media (See Appendix F). For example, a current public charity campaign advertising in widely circulated mainstreamed magazines requests donations for cleft palate surgeries in developing countries. One of the advertisements begins with the headline: “Give a Child With a Cleft A Second Chance At Life” (“Smile Train”, 2004). The text reads, “Today, millions of children in developing countries are suffering with a cleft lip and palate. Condemned to a lifetime of malnutrition, shame and isolation.” The campaign is called the “Smile Train” and visually shows the before and after pictures of an infant, first shamed and isolated, and then happy and smiling, following the surgery. Another advertisement, discussed previously in this chapter, is for a drunk driving campaign. Produced by MADD, the glossy poster promotes a message on college campuses as recently as 2002 that utilized a

black and white silhouetted photograph of a young man in wheelchair, with the caption “You don’t want to end up like this.” Both of these very different media campaigns reinforce the social structures and normative behavior that effectively discriminate against people with disabilities.

At the level of cultural oppression, allies can again prove helpful. Allies can question discriminating practices, campaigns, and attitudes. Allies can also propose positive messages that do not discriminate or devalue people with disabilities. Moreover, allies at this level have an opportunity to promote positive relationships and experiences with people of a variety of abilities.

The third level of oppression is internalized, which is also clearly evidenced in the lives of people with disabilities. Internalized oppression occurs when people with disabilities accept the negative messages used to define them and adopt the social goal of being “normal.” If normalcy is not an achievable goal, through either a cure or being able to “pass as normal,” then isolation often becomes a viable option; hiding from society because of a lack of value and worth. One participant described the way that internalized oppression had isolated a child with a disability:

The girl was fully expecting not to go on to college and that she would need to move in to, at least a board and care facility, if not a nursing home because that was the only way she could survive in the community. Her parents firmly believed that, and that was all she was aspiring to.

The girl’s life options were narrowed down to a bleak and dismal existence because independent living options are often unknown, unavailable, or unaffordable.

To further reinforce the obscurity of community and independent living options, in the United States, there are approximately 800,000 licensed board and care facilities.

It is estimated that roughly 106,000 people with developmental disabilities live in public and private institutions; 1.3 million elderly people and people with disabilities live in nursing facilities, and more than 58,000 people live in psychiatric institutions (National Council on Disability, 2003). At this level of oppression allies can have the most immediate, individual impact. For example, in the story above, the participant also shared, “One of the things my wife was able to do was to work with both the girl and her parents to help them understand that she had choices. She had options and opportunities. Which makes my wife an ally, doesn’t it?”

In summary, people with disabilities continue to experience personal, social, and systematic oppression within the U.S. society. It is imperative that such oppressions are analyzed and exposed for their inherent power over structures which serve to sustain social, cultural, and economic domination over people with disabilities. Analyzing the language of oppression requires the “oppressors,” who are fundamentally privileged over the “oppressed,” to examine the privileges that are inherent, unquestioned qualities they possess. The oppressor may or may not identify as an “oppressor” and may or may not recognize the presence of privileges. Allies are not exempt from this process. Allies are needed at each of the three levels of oppression. However, to be effective, it is crucial that allies look to the big picture and not find themselves in positions of perpetuating discrimination, for example, by focusing on the impaired body or the opportunity to do “good.”

Analysis of Privilege. After analyzing and discussing the multiple mechanisms of power which continue to reinforce and maintain the structures that systematically deny

social, cultural, and economic opportunities for people with disabilities, it is important to recognize and acknowledge the inherent privileges that come to those with power. The framework and organization for this discussion has been borrowed from Peggy McIntosh's seminal article, *White Privilege: Unpacking the Invisible Knapsack* (1989). Speaking of racial privilege, but easily adapted to ability, McIntosh states, "I have come to see white privilege as an invisible package of unearned assets which I can count on cashing in each day, but about which I remain oblivious to" (p.10). McIntosh explains that such unearned assets or privileges are not meant to be obvious. They are meant to be hidden from the consciousness of the perpetrator. Furthermore, McIntosh argues that "power from unearned privilege can look like strength when it is in fact permission to escape or dominate" (p.11).

McIntosh identifies many of her own unearned assets, or the affects of white privilege on her daily life. She develops a list of daily actions, assumptions, or situations in which she is regularly treated differently because she is white. McIntosh encourages the analysis of privilege and "advantaging systems" from multiple perspectives and experiences saying, "We need similarly to examine the daily experience of having age advantage, or ethnic advantage, or physical ability" (p.12).

Pursuing McIntosh's recommendation, following is a list of advantages that this investigator can count on, on a daily basis, because of apparent or perceived physical, cognitive, and psychological abilities. This list of 25 privileges is a unique product of this study; a combination of the researcher's experiences, journaling, and the data. It is also important to acknowledge that it is impossible to clearly separate all of the unearned

privileges that affect this researcher. As a result, many of the privileges listed below are intricately associated with other oppressive systems, including race, class, gender, and sexuality.

1. I am assured access to structures and buildings, both public and private. If I want to visit a friend's house, I am confident in my ability to get in the front door and navigate my way throughout the house with relative ease.
2. If someone watches my movements, they are not simultaneously judging my cognition.
3. When I enter a room or encounter other people, there is typically no apparent reaction over my visual appearance.
4. Since I was a child, I have been assured access to education and granted the opportunities to pursue a quality education if I chose to do so.
5. My educational experiences were grounded in my own personal strengths and my assets were identified and built upon.
6. My parents were never overly fearful about how other children or adults would treat me.
7. My role as a social contributor is not questioned, nor does anyone expect any less of me.
8. I have been raised, and taught to strive for and achieve success.
9. I have always been encouraged to be an independent, critical, self-thinker.

10. If I am being considered for a new job, consideration does not include the employer's previous experience in working with people who appear to be without disabilities.

11. I have choices regarding my medical care and treatment.

12. I am confident that if I schedule a health related appointment, the offices will be structurally accessible, and/or adaptable, for me, including examination equipment. I am also confident that the medical provider will be trained or have experience treating people like me.

13. If prenatal testing had been available when my mother was pregnant with me, medical providers would not have recommended an abortion. When I was born, friends and family did not feel pity, sadness, or concern for my parents.

14. I have the choice to reproduce. If I choose to have children, my decision will not be judged as wrong or inappropriate and my abilities to adequately provide for my children will not be questioned or judged.

15. I have always been treated as a sexual being. I have never been considered asexual. I was never excused from sex education because the information was not necessary.

16. In any given situation, I can disclose as much or as little about my physical or cognitive abilities/disabilities as I choose.

17. I am confident that I can go to any fitness club and access all of the equipment.

18. I am not assumed to be unable or incapable of trying to play any sport.

19. I am confident that other people will be able to communicate with me and understand me, excluding language differences, and people approaching me are similarly confident in my ability.

20. If I don't understand what someone is telling me, they don't automatically raise their voice and speak slowly when they repeat themselves.

21. When I order something in a restaurant the server typically looks at me and asks me directly what I'd like.

22. If I am in a car accident, I am not criticized for driving in the first place.

23. When people describe me, as a person, to others, they do not describe me by my medical history or diagnoses.

24. I can use any telephone, public or private. I can reach the phone, I can see the numbers to dial, and I can hear through the hand piece. Furthermore, I am not limited to calling only those numbers or places who have a teletypewriter (TTY) device.

25. In public, private or medical situations, I don't represent everyone without apparent disabilities. I am not asked to speak for everyone without apparent disabilities. My experiences do not portray the experiences of all people without apparent disabilities.

The 25 statements of unearned assets suggest the pervasiveness of power over structures which privilege some while oppressing others. Those who are reaping the benefits of privilege may or may not recognize their unearned assets. This is important because broad underlying systems of domination require the work of broad systems of alliances, which are firmly dedicated to changing the social structures that perpetuate powerful binaries that position people against one another. As authentic and effective

allies and alliances are formed, it is imperative that the systems of oppression and privilege are recognized and analyzed. People without disabilities must acknowledge their role in perpetuating the oppression of those with disabilities, and both need an understanding of the depth and prevalence of oppression and privilege.

One of the most important realizations from this study and its participants is that allies are basically in a relationship. Like any other relationship, it must be built upon trust, commitment, and mutual agreement. In order to begin to build a relationship based on trust, the ally or potential ally has to identify and look critically at his or her personal position within the oppressive, dominating systems of society.

CHAPTER SIX

Recommendations

The purpose of this research was to explore the experience of being and having allies in the Independent Living Movement (ILM). Experiences shared in this study offer insight into the complexity of allied relationships. These results indicate that despite challenges, the concept of allied participation in the ILM is necessary and desired.

This study produced rich and useful data on the experiences of allied relationships in the ILM. A number of recommendations have emerged through the experiences and knowledge gained from the results and the process of this study. This chapter will introduce and discuss recommendations for research, public health practice, and public health policy.

Recommendations for Research

Disability-Related Research Recommendations. There are two primary recommendations for disability-related research. First, the results of this study indicate a need for consistent conceptualizations of disability. The diverse sample of past and present ILM participants who were interviewed for this study iterated inconsistent definitions of disability. Further research designed to critically analyze diverse perspectives on the definition of disability is a fundamentally important task.

This study was guided by the philosophical foundation of naturalistic inquiry, which acknowledges the complexity of the human experience, the notion that multiple realities can and do exist, the relationship between the individual and their social environment which creates the meaning of an experience, and that “those who have the

experiences are most knowledgeable about them” (DePoy & Gitlin, 1998, p.27). Given the complexity of the conceptualization of disability, further qualitative research designed to explore the definition of disability is recommended. From this perspective, the meaning of disability is known best by those individuals who have experienced the phenomenon directly. The phenomenon, however, should not be simply reduced to the experience of disability by people with disabilities. The disability phenomenon is experienced differently by many people, including friends and family of people with disabilities, healthcare providers and other professionals, and the general public. These diverse entities can provide important perspectives illuminated through qualitative research because each of these entities are involved in the social network that shape and influence the various definitions of disability.

Second, a number of meaningful criticisms were identified and supported through the results of this study, including a detailed analysis of language and the predominant binary thinking that describes disability in the current U.S. culture. Given the importance and necessity of having a social model of disability that addresses both changing systems that perpetuate social inequality, and acknowledges the power and influence of language, further research designed to critically analyze the social model is recommended.

Research on the Allied Relationship in the Independent Living Movement. This research utilized the unique characteristics of the ILM to investigate the experiences and analyze the meanings of being and having allies. The results confirm that there are many complexities for developing and sustaining allied relationships. There are several recommendations for future research on allied relationships in the ILM. First, this study

utilized purposive sampling to identify diverse perspectives, however, due to time and resources some perspectives were not included. Further research utilizing a purposive sampling strategy is recommended to capture the experience of people in different geographical regions, such as the East coast, or rural communities; diverse participants, such as professionals with visible disabilities, youth, or political advocates, and to explore the association between allied relationships and other social inequalities. For example, how do race, ethnicity, class, gender, and/or sexual orientation affect the experience of being and having allies in the Independent Living Movement?

Additionally, the results from this study indicate a strong need for improved dialogue and relationships between the ILM and professionals. Professionals were identified as health and human service workers, health-care providers, personal care attendants, social workers, therapists, etc. Professionals are often intricately involved in shaping the lives and experiences of people with disabilities because disability remains conceptualized as a medical condition. In this position, professionals have a choice to advocate for people with disabilities from two competing perspectives. From one perspective, professionals can reinforce the medical model by advocating for a medical cure for disability. From another perspective, professionals can advocate with and for people with disabilities to change the disability discourse. At first glance, this choice may appear to be a binary. However, it is not. Advocating for a new disability discourse with and for people with disabilities is one potential way of curing the predominantly social problems associated with disability.

The cure for disability is social change. The cure for disability is discourse that reflects the multiple realities of the disability experience. The cure for disability is a society which can accept individual differences and appropriately initiate changes and accommodations that are capable of addressing diverse abilities. Furthermore, the cure for disability is centered around assets, rather than deficits.

In order for social change to affect the professional conceptualization of disability, current conceptualizations must first be identified and critiqued. Research that is designed to explore the perceptions of disability with a diverse sample of health-care providers and professionals would provide crucial information on attitudes, beliefs, and practices that shape professional definitions of disability.

The following list is a summary of recommendations for research related to the experience of being or having allies in the Independent Living Movement. There is a need for further qualitative research designed to:

1. Identify current and prospective allies in the diverse fields that encompass professionals.
2. Investigate relationships between professionals, people with disabilities, and the ILM.
3. Explore the experiences of professionals who have been successful in allied relationships, and who could serve as role models for other professionals.
4. Explore the experience of professionals with disabilities and their relationship with the ILM.

5. Allow participants to self-identify as a person with a disability or not, and similarly, to allow participants to operationally define key study terms, such as disability.

6. Develop and utilize techniques that are capable of adapting to each individual's communication style in order to capture the voices and experiences of people who may be excluded due to communication barriers.

7. Analyze the conceptualization of disability in various academic institutions and health-care training programs, such as medical schools and public health, social work and therapy programs.

Allies and Social Movements. This study also recommends further research on the experience of allies in other social movements. Allies have been identified and discussed as important participants in social movements; however, research designed to explore the concept of allies remains inadequate. Further research on the experiences of working in allied relationships for common causes will foster the development of more allied relationships with greater potential, strength, and understanding.

Several recommendations for research on allied relationships have emerged from this research:

1. Qualitative research methods are recommended to capture the plurality of meaning and experiences by diverse participants.

2. It is important to conduct analyses of similar studies to determine differences and similarities between various allied relationships.

3. Research designs that allow participants to operationalize key terms and concepts is crucial.

Recommendations for Public Health Research. There are three primary recommendations for public health research. First, it is imperative that the experiences of people with disabilities be included in health promotion research. Second, the complex realities of people with disabilities could be captured in public health research and theories. It is therefore recommended that social models of disability be incorporated into public health studies. Furthermore, it is important that such research be conducted from the social model perspective, rather than the predominant individual and medical models. Third, public health research engaging in the dialogue and desire to develop a consistent and inclusive definition of disability is vital.

Recommendations for Public Health Practice

The results of this study inspired a number of recommendations for public health practice. First and foremost, public health professionals are challenged with the immediate necessity of shifting their perspective on disability and people with disabilities from one of deficits and needs, to one of assets and capabilities. This perspective is not new for public health; in fact, many professionals have already made a similar shift in relation to communities. In *Mapping Community Capacity*, McNight & Kretzmann (1999) effectively argue that traditional needs-oriented perspectives are inadequate for initiating real change in communities, and, rather, an assessment of community assets and capacities should be promoted. They state that “communities have never been built upon their deficiencies. Building community has always depended upon mobilizing the capacities and assets of a people and a place” (p. 167). A similar perspective is recommended for people as everyone has assets and deficits. People with disabilities

have long been identified solely on the basis of their deficits, while their assets and capacities have been socially repressed and devalued.

Second, the success of programs, interventions, or innovations that are designed for people with disabilities are greatly enhanced when designed by or with people with disabilities. This study reaffirms the importance of involving a diverse representation of people with disabilities in the development and management of programs and services that affect their lives and experiences. It is further recommended that health promotion programs and public health practitioners involve people with disabilities in designing and developing interventions. Contacting and utilizing the expertise of a local Independent Living Center and potentially involving staff and consumers should be an important consideration for public health practitioners. Involving diverse people with experiences with disability will help prioritize issues that are crucially important to people with disabilities and create meaningful programs and services.

Third, steeped in the process and results of this study are over 20 recommendations for being and having allies. These recommendations were originally intended for public health professionals, but would have a greater impact if recommended for everyone in general. The results from this study indicate that the allied relationship is reciprocal and that there are qualities necessary for both those who are allies and those who have allies. This research has identified a number of characteristics that are necessary for both those who are allies and those who have allies, including: respect, value, an asset/capacity-based perspective, communication, and an understanding of current and historical socio-cultural influences. In addition, several other

recommendations for being and having allies emerged from this study, each of which is introduced below.

1. Acknowledge that professionals and public health practitioners include people with a wide variety of physical, cognitive, and emotional abilities.
2. Identify language that is deficit oriented – in articles, communication, health promotion programs, organizational statements, etc.
3. Be aware of, and do not use, language that perpetuates the devaluation and discrimination against people with disabilities.
4. Encourage family, friends, and co-workers to similarly refrain from using language that is discriminatory in tone or connotation.
5. Speak out against language and behavior that devalues people with disabilities.
6. It is important for professionals to challenge current conceptualizations and redefine professionalism. As one study participant eloquently stated, “Professionalism is actually not about how many degrees you have, or how many classroom hours you’ve had; it’s the extent to which you facilitate choice.”
7. Value, respect, and openness to difference were all identified as crucial characteristics of participants in allied relationships.
8. Read books, articles, or stories about people with disabilities.
9. Attend conferences and raise questions about disability related issues.
10. Identify goals and communicate with the individuals/groups that you are working with.

11. Know what resources or skills you have to offer, and are willing to offer, in an allied relationship.

12. Acknowledge that being involved in an allied relationship may at times be difficult and painful, but over time sincere allies will demonstrate their value and dedication.

13. Similarly, it is important for public health professionals to ask questions and refrain from know-it-all attitudes and approaches.

14. Be prepared to make mistakes, take risks, and learn from these experiences.

15. Communication was identified in this research as an important quality affecting the outcome and success and allied relationship. Encouraging and facilitating effective communication will strengthen and clarify the meaning of allied relationships.

16. Observe and analyze community interactions between people. Who are people with disabilities? Are people with visible, apparent, or perceived disabilities treated differently by others? When a person with a disability is identified, what is the identifiable characteristic? Does the identifiable characteristic lead to any judgments or preconceptions of the individual?

17. Talk with your friends, family members, and co-workers about disability related issues and experiences with disability.

18. Question personal beliefs and judgments. Ask questions of yourself including: How comfortable are you with people of diverse abilities? Do you stereotype

people with disabilities? What would make being an ally challenging for you? What could you offer in an allied relationship?

19. Develop a social consciousness - an understanding, recognition, or critical analysis of how experiences of race, ethnicity, gender, ability and perceived ability, or sexual orientation relate to past and present society.

20. Seek out your position in an allied relationship. Don't wait for an invitation by an individual or organization.

21. Identify and promote successful relationships and potential role models for professionals effectively and appropriately involved in allied relationships.

Recommendations for Public Health Policy

The primary recommendation for public health policy identified in this study is the challenge of re-evaluating language and discourse on disability in public health. Current public health policy addresses disability from a prevention and medical perspective. The results of this study indicate a serious need for public health policies to re-evaluate the language that is used. For example, the mission statement for the Centers for Disease Control and Prevention is "To promote health and quality of life by preventing and controlling disease, injury, and disability" ("About CDC," n.d.).

Public health professionals must engage in dialogue about the meaning of statements such as "preventing disability." Preventing disability is a difficult statement because it indirectly implies a desire to eradicate disability, further implying that people with disabilities have little value. A similar statement oriented towards women, or other minority groups would not be tolerated or condoned. Is it the true goal of public health to

prevent disability? Or is the goal of public health to prevent death, illness, and injury among a population of people with diverse and fluctuating abilities?

Similarly, it is also recommended that public health policy is adequately informed by research that explores the ethical considerations of current medical research, technology, and practice designed to control the future outcome of the human race. For example, the widespread development and use of pre-natal medical technologies have raised a number of questions that require discussion: What are the consequences of medical technology that have the capability of identifying and reproducing a particular type of person? What are the benefits and dangers of such technology? What are the effects of technology that is not only able to identify a potential “deficit” in a fetus, such as Down’s Syndrome, or Cerebral Palsy, but also recommends termination of such a fetus, on people with disabilities? Are the assumptions that a fetus without Down’s Syndrome, or Cerebral Palsy, will live a happier, more fulfilling life? If so, why?

The questions raised in this study, and the recommendations discussed, are difficult and complex, but nonetheless fundamentally important to the successful formation of allied relationships in the Independent Living Movement. It is sincerely hoped that this research will encourage dialogue around the experience of being and having allies in many social movements and better prepare people to participate in allied relationships.

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APPENDIX A

Interview Questions

Opening Questions - General

- 1) What is disability?
 - 1.a) What is the continuum of disability?
 - 1.b) Are there other continuum's?
- 2) What is independent living?
- 3) Tell me about your experiences in the ILM.
- 4) What led to your getting involved in the ILM?
- 5) How long have you been involved in the ILM?
- 6) What does ILM mean to you? Past? Present?
- 7) Tell me about the relationships you have with other participants.
- 8) Can you describe some of the best working relationships?
- 9) Can you describe some of the worst working relationships?
- 10) What is an ally?
- 11) Do you consider yourself an ally?
- 12) Do you identify as having a disability?
- 13) Describe your relationships with people with and without disabilities.
- 14) Who do you consider/describe as allies to the ILM?
- 15) Describe the benefits to you personally in being involved in the ILM.
- 16) Do you feel there is tension between allies and other participants?
- 17) How have your relationships changed over time? Elaborate.

Allies

1. Describe the purpose of being an ally.
2. Do you feel allies are necessary participants? Describe.
3. What do you feel you contribute to the ILM?
4. Do you feel that others recognize your contributions?
5. Describe the benefits of being an ally to the ILM.
6. Tell me about the challenges of being an ally.
7. Tell me about building & maintaining trust as a new ally (participant).

Having Allies

1. Describe the purpose of having an ally.
2. Do you feel allies are necessary participants? Describe.
3. Describe the benefits of having an ally to the ILM.
4. Tell me about the challenges of having an ally.
5. Tell me about building & maintaining trust with new allies.

APPENDIX B

HS-IRB Research Protocol

Statement of Purpose and Justification

The purpose of this research is to explore the role of ally in the Independent Living Movement (ILM). Spearheaded by Ed Roberts, in Berkeley, California, the ILM opened the first Independent Living Center (ILC) in 1972. In the 30 years since, the ILM has grown to an international movement with more than 500 independent living centers worldwide. Using qualitative methodology, this research will provide people who participate in the Independent Living Movement, as both beneficiaries and allies, an opportunity to share their experiences in a movement created by and for people with disabilities. Specifically, this study will examine the unique challenges, contributions, risks, and benefits of being allies and having allies in this important social movement.

This study has five key objectives: (1) to explore the role of allies in the ILM as experienced by both movement allies and beneficiaries, (2) to provide an opportunity for people to reflect on and articulate their experiences in the Independent Living Movement, (3) to produce useful data for public health professionals and community advocates to promote the independent living philosophy and participate in the ILM, (4) to add to the literature on social movement participation, the Independent Living Movement, and community organizing, and (5) to facilitate and stimulate discussion of the role and relationships of allies in community organizing for health.

In a multicultural society where our differences are increasingly abundant it is becoming ever more important to have the capacity and desire to forge relationships

across these differences and work amongst a variety of people to achieve a common goal. Additionally, since life situations are constantly changing, no one ever really knows when they will need the help of others. Recognizing the imminence of change and the expanding diversity among populations this proposed research study is at the forefront of increasing our understanding of the challenges, risks, and benefits of people uniting across differences and working together towards a unified vision.

Moreover, the proposed research study may have significance to several disciplines. In the social science field, this research has the capacity to influence and encourage future research studies relating to the role of allies and alliances in other social movements. In the health promotion and community studies disciplines, this research will assist community activists in becoming better change agents and more equipped to work closely and effectively with people with disabilities. This research will illustrate ways in which people have worked within the ILM to improve the lives of people with disabilities and provide role models for other community activists and public health professionals to work successfully and appropriately within the Independent Living Movement. Most importantly, this research will enhance relationships and ultimately cultivate the development of improved health promotion programs designed specifically to enrich the health and well being of people with disabilities.

Research Questions

This research is designed to explore the role of allies in the Independent Living Movement as experienced by both allies and beneficiaries.

Specifically, this research will pose the following questions:

1. How are “ally” and “beneficiary” defined by individuals, with different perspectives and life experiences, who are participating in the Independent Living Movement?
2. What is the experience of being or having an ally to individuals participating in the movement?
3. What are the assumptions, held by different people involved in the Independent Living Movement, about the allied relationship?
4. What is the meaning of being or having an ally in the Independent Living Movement?

Methods

Subjects

This study will utilize a purposive sampling strategy to create a convenient sample of 10 to 15 participants, with and without disabilities, aged 18 and over. Sampling recruitment will begin in the San Francisco Bay Area with Independent Living Center staff and board members, followed by snowball sampling to generate additional participants. Initially, potential participants will be identified through key contacts already known to the researcher. These key contacts include individuals who are currently working in an Independent Living Center (ILC), previous ILC staff members, professionals who work with people with disabilities and the local ILC, and community activists. The goal of this sampling is to collect as many diverse perspectives among people who participate in the Independent Living Movement as an ally or beneficiary.

As participants are identified, key informants will initially contact and ask the possible participant for permission to give the researcher contact information. Contact information for potential participants will include email address and phone number, additionally, the key informant will ask the potential participant which is their preferred method of contact.

Following the initial contact made by the key informant, the researcher will contact potential participants and invite them to join the study. If they express interest, the researcher will mail or email the study abstract (See Appendix E) and set up an interview. Upon receiving the abstract, potential participants will have the opportunity to let the researcher know if they would like to continue with the process and participate in the study.

At the beginning of each interview the researcher will present and discuss the informed consent materials. Participants will be told that declining to participate, or ending the interview, will not affect their access to services from the Independent Living Movement. The researcher will inform all potential participants directly if they are to be interviewed or not. Additionally, the researcher will maintain a list of all potential participants.

Risk

The risk for this research is minimal and fits appropriately within the guidelines of Category “A” of SJSU HS-IRB. The only foreseeable risks are those associated with the discussion of personal experiences. However, since the interview will be conducted with an open-ended protocol, participants may limit disclosure as they see fit.

Compensation

Research participants will not be compensated for their participation. The researcher will present individual's with small "gifts" as a token of appreciation for sharing their experiences and time.

Materials and Procedures

Participants will be asked to take part in a one-on-one interview, with the researcher, utilizing open ended questions regarding their experiences in the Independent Living Movement. The interviews will take place from June through August, 2003. It is a high priority for the researcher to conduct these interviews in a confidential, quiet, and comfortable environment, such as the participant's home. The interview protocol is designed to last approximately 60-90 minutes. Interview questions will include questions asked to each participant, but ultimately, each interview will be tailored to reflect the unique experiences of each participant (See Interview Questions, Appendix B).

Interviews will be audio taped, using a recorder and microphone, followed by transcription. Each interview will be edited by the researcher, against the audio recorded interview to insure accurate transcription. When possible, informants will be consulted throughout the transcription process to assure that their experiences and meanings are accurately recorded. The researcher will utilize field notes to supplement transcriptions, adding context and the researcher's perspective at the time of the interview.

Confidentiality

The confidentiality of participants will be protected to the best of the researcher's abilities. Participant names and other identifying characteristics will be coded by the

researcher. Any document containing identifying characteristics of individual participants will be viewed only by the research team and kept separate from all other research material in a locked file cabinet in the researcher's home office, in Capitola, California. Confidentiality will continue to be upheld when findings are reported in a summarizing and thematic fashion. Individual quotes may be used without containing any identifying characteristics. All materials identifying individual informants will be destroyed after all research findings have been written. However, as required by law, all research data will be kept for at least three years before any data will be destroyed.

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<http://www.sjsu.edu/depts/casa/depts/hs.html>

APPENDIX C

Agreement to Participate in Research

Responsible Investigator: Anji Buckner

Title of Protocol: *A qualitative study of the experience of being or having an ally in the independent living movement.*

- ♦ I have been asked to participate in a research study investigating the role of allies in the independent living movement.
- ♦ I will be asked to participate in a tape recorded interview, and follow-up interviews as needed, each lasting up to 1.5 hours. I understand that I may request breaks during the interview.
- ♦ The purpose of the interview is to share my experiences in the Independent Living Movement. I may find the process of sharing these experiences rewarding and empowering.
- ♦ Although the results of this study may be published, no information that could identify me will be included. If published, the study may include quotes, but will not identify me by my real name or by identifying characteristics.
- ♦ I understand that I will not be monetarily compensated for my participation in this study.

Initial _____

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<http://www.sjsu.edu/depts/casa/dept/hs.html>

- ♦ Questions about this research may be addressed to Anji Buckner, PO Box 1941, Capitola, CA 95010 (831) 479-9733. Complaints about the research may be presented to Edward Mamary, MPH Department Chair, (408) 924-2986. Questions about research subjects' rights, or research-related injury may be presented to Nabil Ibrahim, Ph.D., Associate Vice President, Graduate Studies and Research, at (408) 924-2480.
- ♦ I understand that my consent is being given voluntarily. I understand that I may refuse to participate in the entire study or in any part of the study. If I decide to participate in the study, I am free to withdraw at any time.
- ♦ No service of any kind to which a person would otherwise be entitled from San José State University will be lost or jeopardized if a person chooses not to participate in the study.
- ♦ At the time that I sign this consent form, I will receive a copy of it for my records, signed and dated by the investigator.
- ♦ I understand that my signature indicates my agreement to willingly participate in this study.
- ♦ The signature of the researcher on this document indicates agreement to include the above-named person in the research and asserts that the subject has been fully informed of his or her rights.

Participant's Signature

Date

Researcher's Signature

Date

San José State
UNIVERSITY

**Office of the Academic
Vice President**
Academic Vice President
Graduate Studies and Research

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APPENDIX D

IRB Approval Letter

To: Anji Buckner-Capone
P.O. Box 1941
Capitola, CA 95010

From: Pam Stacks,
Interim Academic Vice-President
Graduate Studies & Research

Date: July 29, 2003

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

“A Qualitative Study of the Role of Ally in the Independent
Living Movement.”

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Pam Stacks immediately. Injury includes but is not limited to bodily harm, psychological trauma, and release of potentially damaging personal information. This approval for the human subjects portion of your project is in effect for one year, and data collection beyond July 29, 2004 requires an extension request.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services that the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

cc: Dr Kathleen Roe

The California State University:
Chancellor's Office
Bakersfield, Channel Islands, Chico,
Dominguez Hills, Fresno, Fullerton,
Hayward, Humboldt, Long Beach,
Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San José, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

APPENDIX E

Study Abstract

The purpose of this study is to explore the role of ally in the Independent Living Movement. Using qualitative methodology, this study will examine the unique challenges, contributions, risks, and benefits of being allies and having allies in this important social movement. This study will involve 10-15 participants, with and without disabilities who have participated in the Independent Living Movement as staff, professionals, and/or community disability rights activists. The goal is to collect many diverse perspectives among people who participate in the Independent Living Movement as an ally or beneficiary.

This study has possible far reaching implications including an improved understanding of the challenges, risks and benefits of people uniting across differences and working together towards a unified vision. Moreover, this research has the potential to enhance relationships and ultimately cultivate the development of improved health promotion programs designed specifically to enrich the health and well being of people with disabilities.

APPENDIX F

Smile Train Advertisement

Give A Child With A Cleft A Second Chance At Life.

Today, millions of children in developing countries are suffering with cleft lip and palate. Condemned to a lifetime of malnutrition, shame and isolation.

The good news is that virtually all of these children can be helped and their clefts repaired. That is the mission of The Smile Train. We empower local surgeons in developing countries to provide this life-changing free cleft surgery which takes as little as 45 minutes and costs as little as \$250. It gives desperate children not just a new smile—but a new life.

The Smile Train will deliver free cleft surgery to more than 35,000 children this year, all over the world. From Asia to Africa, from South America to Russia, The Smile Train helps children who have no place else to turn.

But we can't do it without your help. Send us a donation today and we'll use it to give someone a second chance at life.

YES, I want to give a child a second chance at life.

- ☐ \$250 Provides cleft lip surgery for one child.
☐ \$125 Covers half the cost of one surgery.
☐ \$ 50 Provides medications for one surgery.
☐ \$ _ We'll gratefully accept any amount.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

eMail _____

Charge my gift to my credit card:

☐ Visa ☐ MasterCard ☐ AMEX

Account No. _____ Exp. Date _____

Signature _____

Send this coupon with your donation to:
The Smile Train-Dept. Mag.
P.O. Box 96231
Washington, DC 20090-6231

3000-00-300-09

**100% of your donation goes towards programs —
 0% goes towards overhead.**

TheSmileTrain
 Changing The World One Smile At A Time.

1-877-KID-SMILE www.smiletrain.org

*All non-program expenses, such as overhead and fundraising, are paid for with start-up grants from our founding supporters. The Smile Train is a 501 (c)(3) nonprofit recognized by the IRS, and all donations to The Smile Train are tax-deductible in accordance with IRS regulations. © 2003 The Smile Train.